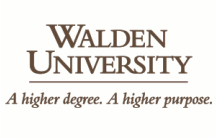

2018

Effects of Cancer Staging on Maternal Coping and Mother-Child Communication Patterns Among Breast Cancer Survivors

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This is to certify that the doctoral dissertation by

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has been found to be complete and satisfactory in all respects,
and that any and all revisions required by
the review committee have been made.

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Abstract

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by

Kevin Michael Lycke

MSW, State University of New York at Stony Brook, 2000

BA, State University of New York at Old Westbury, 1989

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Human Services/Clinical Social Work

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May 2018

Abstract

Few researchers have examined the relationship between earlier stages of breast cancer and its effect on staging of the disease process and the co-occurring coping and communication patterns between mothers and their children. The purposes of this qualitative study with a multiple case study design were to examine (a) coping mechanisms that mothers used to manage the uncertainty of their breast cancer status and (b) the impact of early-stage breast cancer on communication patterns between mothers and their children. The Lazarus and Folkman theory of psychological coping and the McMaster family systems communication theory informed the conceptual framework for the data analysis. The instrument for data gathering was a researcher-designed, semistructured interview guide. The sample consisted of 20 maternal breast cancer survivors and their children. Qualitative data analysis involved member checking and content analysis to confirm the frequency of similarities and differences occurring among participant responses. Key findings were that participants: (a) adapted to their diagnosis while refining their preexisting coping mechanisms, (b) found motherhood to be a source of emotional strength throughout the duration of their cancer process, and (c) managed changes in communication with their children during each phase of cancer treatment by using combinations of communication styles. Oncology social workers can use the findings of this study as an opportunity to develop models of best practices that are effective in helping patients cope with early stage breast cancer. The findings of this study impact social change by informing clinical social work with an effective paradigm that helps mothers and their children cope with the different phases of breast cancer.

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Dedication

This dissertation is dedicated to my maternal grandmother, Ann Marie; my parents, Ann Marie (Rie) and William (Bill) Charles, Sr.; my siblings: William (Billy) Charles, Jr., Nancy Marie, Kristine Marie; my life partner, Clyde G. Barton; my sister-in-law, Laura Marie; my mother-in-law, Sylvia M. Barton, RN; and my nieces and nephews: Carly Ann, Andrew William, Jack Fredrick, Máire Kristine, and Madeleine Grace (Maddie).

Kristine Marie, my youngest sister, inspired the rationale for my study by her own breast cancer survivorship. She continuously motivates me by her courage, insights, spirit, and unyielding patience. She is truly a scholar-practitioner in the making.

Clyde, my life partner, is a saving grace and rock. I would have *never* been able to manage this task without you on so many levels. Words can only cast shadows, but your love and faith in my capabilities scorched every corner of self-doubt and distress. Thank you.

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Chapter 1: Introduction to the Study

Introduction

In 2014, more than a quarter of a million of women received a breast cancer diagnosis in the United States (American Cancer Society [ACS], 2015). In the same year, New York State had 14,000 women newly diagnosed with breast cancer (National Breast Cancer Foundation [NBCF], 2015). Of these 14,000 women, 2,400 resided on Long Island. In the 1990s, experts studied cancer clusters and found higher rates of breast cancer among women on Long Island when compared with other parts of the country (Centers for Disease Control and Prevention [CDC], 2012).

After 20 years of data collection for more than 10 studies, experts have found little evidence for the effects of environment on disease (Winn, 2005). Epidemiologists have purported that family history, ethnicity (e.g., higher incidence of breast cancer among women of Ashkenazi ancestry), delayed childbearing age, cigarette smoking, and increased alcohol consumption are important factors in the development of breast cancer (National Cancer Institute [NCI], 2015b). Obesity and sedentary lifestyle may also increase the risk of breast cancer (ACS, 2015).

During the breast cancer diagnostic and treatment process, women face physical, psychological, and emotional challenges related to the disease itself and to the side effects of cancer treatment (Oktay, 1998). Mothers raising young/adolescent children have an additional responsibility for balancing their medical concerns with the needs of their children. Furthermore, they must deal with the physical and psychosocial components and consequences of their breast cancer (Batenburg & Das, 2014; Donovan-Kicken, Tollison, & Goins, 2012).

Communication is a key factor in positive parenting and in creating and maintaining effective parent-child relationships. Mothers often believe that breast cancer negatively affects their ability to parent, particularly in regard to communicating about the breast cancer (Davey, Tubbs, Kissil, & Niño, 2011). However, mothers can use their breast cancer experiences to create meaningful dialogue and open communication patterns with their children (Lewis & Darby, 2004; Molina et al., 2014). This interactional relational process can foster the sharing of cancer-related fears and concerns, hopes, and everyday issues (Lagerdahl, Moynihan, & Stollery, 2014; Tirassa & Bosco, 2008).

Furthermore, as with all cancer diagnoses, maternal breast cancer survivors must consider the emotional effects of the possibility of the cancer's recurrence. While this possibility is less likely for early stage (0 through IIB) breast cancer survivors than for those diagnosed at a later stage (IIIA/B through IV), as with any chronic, life-threatening illness, the pathological aspects of cancer come with no guarantees (Lewis, 2009).

Health-related uncertainty may be a motivating factor in mothers' creation of intentional communication patterns with their children through a process of *socioemotional selectivity* based on altered perceptions of time. Maternal breast cancer survivors, motivated by their cancer crisis, could resolve uncertainty-related anxiety by creating *effective communication* patterns with their children. Effective communication involves open and direct dialogue with intentions for decision-making and problem-solving (Donovan-Kicken et al., 2010). The use of effective communication could create and/or maintain deeper connections between mothers and their children (Fisher, 2010).

Maternal breast cancer survivors might proactively use their breast cancer experience(s) by using socioemotional selectivity as a guide to construct effective communication strategies

with their children. By constructing psychological and emotional networks with their children through effective communication, mothers can adapt to changes in their parental role. Importantly, this process may help mothers effectively cope with breast cancer, thereby improving the quality of life for mothers and their children. The psychosocial health of breast cancer survivors in relationship to their motherhood identities is thus worth studying.

This chapter includes the background of the study, the problem statement, a discussion of the study's purpose, the research questions, and discussions of the conceptual framework of the study, nature of the study, definitions, assumptions, scope and delimitations, limitations, significance of the study to practice, significance to theory, and significance to social change. The chapter ends with a summary, conclusion, and transition to Chapter 2.

Background of the Study

In this section, I present contextual information to identify the important components of this study: (a) the broadening of research inquiry to include the effects of cancer on psychosocial functioning, (b) the effects of cancer on parental identity, particularly that of mothers, (c) cancer staging, (d) the effects of cancer staging on psychosocial functioning and time perception (i.e., altered perception of time because of chronic, life-threatening illness), and (e) the impact of health uncertainty on relationships and communication patterns.

Historical Overview

For over a century, researchers have studied the effects of cancer on caregivers and families (Lewis, 2004). The first generation of studies appeared as clinical presentations and included recommendations for how to minimize disruptions to the patient and the patient's spouse (Lewis & Darby, 2004). The second generation emerged in the 1970s and 1980s and

primarily included cross-sectional, descriptive designs focusing mainly on the caregiver or the patient's spouse (Sigal, Perry, Robbins, Gagne´, & Nassif, 2003).

In the third generation of studies, investigators used complex statistical analyses to examine the processes and relationships between cancer patient survivorship and its effects on family members (Lewis & Darby, 2004). Researchers used such analyses to understand (a) how the cancer informed other family members' behaviors, (b) how family members successfully or unsuccessfully managed the illness, and (c) why cancer diagnoses of a parent and/or family member negatively affected children (Ares, Label, & Bielajew, 2014; Batenburg & Das, 2014; Donovan-Kicken et al., 2010). During this generation of research, cancer researchers identified the importance of communication between cancer survivors and family members. Children of cancer survivors were encouraged to discuss fears of recurrence, grief over losing a healthy parent, depression due to helplessness, and guilt for feeling angry about the situation (Lagerdahl et al., 2014).

Researchers conducting the fourth generation of studies developed rigorous intervention studies for caregivers and family members (Krueger, 2004). However, based on what was already known about families (i.e., what affected them and whether or not they managed or managed the cancer well), the focus was limited to short-term survivors and their families and did not include long-term survivors (Ares et al., 2014). This represents an important gap in research, as people with cancer are now living longer due to earlier cancer detection, improved cancer screenings, and medical advances in cancer treatment. Moreover, cancer survivorship affects interpersonal relationships, particularly relationships within family systems (Lagerdahl et al., 2014).

Parental Cancer

In a seminal study, Semple and McCance (2010) found that at the time of a cancer diagnosis, parents experienced anxiety and sorrow about missing significant events in the lives of their children. Moreover, parents had a fear of telling their children about their diagnosis. They felt helpless during hospital stays and attributed this feeling to long periods of alienation from their children. Parents had an ardent desire to communicate their needs, especially in order to prepare their children for the uncertainties of a cancer diagnosis, treatment, and recovery.

Semple and McCance (2010) also found that parents experienced many debilitating effects from cancer treatments, which had an impact on family activities, especially those that involved eating. Often role changes occurred within the family. After treatment, parents living with cancer often experienced familial encouragement through communication, resulting in a desire to get back to normalcy (i.e., the nuances of day-to-day life). Moreover, parents had an increased appreciation for life, which helped them manage their anxiety about uncertainties. Parents reported that communication was critical in strengthening the emotional and psychological bonds between parent and child (Semple & McCance, 2010).

According to Clark (2001), parents do not always agree on how to communicate with their children about their cancer diagnosis. Lagerdahl et al. (2014) found that some parents hoped to hide the difficulties of cancer from their children or, through avoidance, expected that their children would somehow develop an understanding without having a discussion. Importantly, families need to examine what they are doing and not avoid discussing cancer and its treatments (Lillquist & Abramson, 2002). Zebrack and Chesler (2001) found a relationship between withholding medical information and reduced family cohesiveness. In addition, worse health was

seen within families that withheld information in order to avoid distress. Thus, withholding information to protect or buffer children does not appear to be a healthy or supportive approach.

For parents with cancer, concerns about their children were essentially universal (Osborn, 2007). Ideally, cancer centers require knowledgeable mental health providers be available to assist patients in performing the critical role of parenting (Manne, 2004). There exist some guiding principles that can be useful to parents in helping their children cope with parental cancer. According to Golby (2014), oncology social workers can teach these principles to other individuals in the client's oncology support system. Osborn (2004) found that as clinicians became more comfortable with parental cancer concerns and recommendations, patients were more likely to share concerns with their oncology teams and their children. Sharing these concerns built an alliance with the patient's health care providers and offered an opportunity to help thousands of children whose parent had cancer.

Some parents tend to wait for their children to bring up the topic of cancer for discussion (Sahler et al., 1997). According to Lewis and Darby (2004), parents sometimes try to protect their children from anxiety by avoiding communication about their illness; ironically, this evasion of the topic can actually increase children's anxieties (Weaver, Rowland, Alfano, & McNeel, 2010). Wong, Cavanaugh, MacLeamy, Soujourner-Nelson, and Koopman (2010) found that parents also wondered how much information to provide regarding side effects of treatment such as anxiety, depression, fatigue, irritability, physical challenges, hair loss, and so on.

More difficult to discern is whether parents correctly interpret and communicate how the diagnosis affects their offspring (Lillquist & Abramson, 2002). Communication is a factor in psychosocial functioning, and it is important for parent and child to discuss the cancer experience, especially how they are coping (Mazzotti, Serrano, Sebastiani, & Marchetti, 2012).

The skills of effective communication and expressive coping appear to be the cornerstones of maintaining cohesive emotional bonds between parent and child (Molina et al., 2014; Kayser, Sormanti, & Strainchamps, 1999).

Impact of Cancer on Parental Identity

Concern about not being able to function as an effective caregiver is a worry often shared by caregivers with chronic, life-threatening illnesses (Golby, 2014). Moreover, mothers with breast cancer face both physical limitations and psychological challenges (Molina et al., 2014). Anxiety and depression often result from contradictory narratives about the ideals and expectations of motherhood (Fobair et al., 2009). Thus, emotional conflicts can arise from a mother's perception of her cancer diagnosis and its impact on her abilities to function as a caregiver.

Golby (2014) found that mothers with breast cancer often believed that their diagnosis and treatment process weakened their emotional attachments with their children. Such concerns often result in anxiety and depression, risk factors that compromise psychological resilience and coping (Zebrack, Jaehee, Petersen, & Ganz, 2008). A woman's function as a mother, although socially constructed, becomes problematic when she cannot not optimally perform in the manner expected of her. Foran-Tuller, O'Hea, Moon, and Miller (2012) found that mothers diagnosed with cancer faced many psychosocial challenges surrounding their maternal identity and function. Importantly for this study, prognosis and stage of cancer were factors in whether mothers developed a preoccupation with time and in how they used this perception of limited time to structure parent-child relationships.

Processes and Complexities of Breast Cancer Diagnosis

According to breast cancer experts (Jardines et al., 2015), a diagnosis of breast cancer involves three distinct phases: (a) initial diagnosis, (b) surgical diagnosis, and (c) cancer staging. Prior to a determination of cancer stage, individuals undergo various medical procedures in order for oncologists to make accurate diagnoses. Pre-cancer staging interventions often include at least two of the following: general physical exam or medical screening, mammogram, ultrasound, MRI, biopsy, lab tests, and more invasive surgical procedures (e.g., mastectomy). Surgeons and oncologists consider breast cancer staging to be a continuation of the initial and surgical diagnoses (Sparano, 2016).

System of Breast Cancer Staging

Oncologists use the tumor nodes metastasis (TNM) system of cancer staging for people diagnosed with tumors (see Table 1). Cancer stage is usually determined by (a) size of tumor, (b) location of the original tumor, (c) extent of lymph node involvement, and (d) absence or presence of metastasis, or spread, of the cancer (ACS, 2015). Oncologists do not use the TNM system for many cancers in or around the brain, Hodgkin disease and other lymphomas, or some childhood cancers.

Table 1

TNM Classification of Breast Cancer Stages

Stage	Definition
0	Carcinoma in situ: Abnormal cells present only in cells in which they developed.
IA	Tumor is 2 cm or smaller and has not spread to the lymph nodes.
IB	Evidence of small cancer clusters between .2 and 2.0 mm in lymph nodes.
IIA	Tumor measures 2 cm and has spread to the axillary lymph nodes, or the tumor is larger than 2 cm but not larger than 5 cm and there is no spread to the axillary lymph nodes.
IIB	Tumor is larger than 2 cm but not larger than 5 cm; cancer has spread to 1-3 axillary lymph nodes or lymph nodes near the breast bone.
IIIA	Invasive breast cancer; cancer spread to 4-9 axillary lymph nodes or lymph nodes near the breast bone; tumor is larger than 5 cm.
IIIB	Cancer spread to 9 or more axillary lymph nodes, breastbone, and chest wall.
IIIC	Cancer spread to 10 or more axillary lymph nodes, lymph nodes above or below the collarbone, and lymph nodes near the chest wall.
IV	Extensive spread of cancer to distant tissues and organs.

Note. Adapted from TNM Classification of Breast Cancer Stages (NCI, March 2015)

The TNM system generates codes to describe the stage of a tumor. Doctors use data from the TNM to (a) help plan treatment, (b) estimate prognosis, and (c) identify patients' suitability

for clinical trials. Physicians inform patients of their stage as part of their right to personal health information, as knowledge of their cancer staging may help people better understand the nature of their illness and make appropriate provisions for their lives and the lives of their loved ones.

Coping with Cancer

Traditionally, scholars in behavioral psychology have categorized coping as a psychological process. Coping mechanisms are the ways in which individuals choose to deal with, work through, or overcome events often beyond their control; these mechanisms can help individuals contend with internal and environmental stress. If an individual perceives that they cannot manage an internal or external conflict, emotional regulation becomes increasingly difficult. Baqutayan (2011) purported that having intact social support systems (e.g., family members, friends, etc.) is an important coping mechanism. The ability to communicate and express ideas and feelings is also a key coping mechanism (Trevithick, 2012).

Oncology experts have found that individuals use an array of coping strategies throughout the cancer continuum (Tao, Jiang, Liu, Aungsuroch, & Tao, 2015). Some individuals opt for negative coping methods such as psychological detachment and avoidance, while others use healthier methods that are proactive and problem-solution focused. A patient's coping strategies often begin while they are awaiting confirmation of a cancer diagnosis and often take the form of intense anticipatory anxiety. Individuals diagnosed with cancer must then deal with cancer prognosis, staging, treatment, and the uncertainties that come with cancer.

Importantly, a cancer diagnosis affects the entire family. According to researchers Surbone, Zwitter, Rajer, & Stiefel (2013), both cancer survivors and their families can use effective modes of communication that are open, direct, and problem-solution focused in order to manage the psychological and emotional effects of cancer.

The Effects of Cancer Diagnosis and Staging on Communication

Some investigators (Sada, Street, Singh, Shada, & Naik, 2011) have studied communication patterns between cancer survivors and their primary care professionals (e.g., oncologists). Barnes et al. (2002) explored communication patterns between children and mothers with Stage I and Stage II breast cancer. Others (Levin, Moreno, Silvester, & Kissane, 2010; O'Mahony, Hegarty, & McCarthy, 2010; Trice & Prigerson, 2009;) have examined communication patterns among patients with late-stage disease (Stage IV), their loved ones, and primary care teams. Missing from this body of literature, however, are studies on communication during earlier stages of a cancer diagnosis and the related parent-child communication. Furthermore, few researchers have included in-depth explorations of individual affective reactions to a cancer diagnosis and cancer staging, as well as those reactions' effects on the relationship between mother and child (Trice & Prigerson, 2009).

Statement of the Problem

Professionals are often unaware of coping mechanisms used by breast cancer survivors at the time of diagnosis and throughout different stages of cancer. Furthermore, how early-stage breast cancer shapes communication patterns between mothers and their children remains unknown (Waters & Porter, 2014). The complexities of the relationship between early breast cancer diagnosis/staging, coping between mother and child, and communication processes need examination to establish points of possible intervention to facilitate communication and strengthen familial relationships.

Nature of the Study

This qualitative, multiple case study provided an in-depth understanding of how mothers' cancer stages affect communication with their children and of the coping mechanisms mothers

use to manage cancer staging. Using a sample of 20 maternal breast cancer survivors on Long Island, New York, I compared and contrasted mothers' understanding of how cancer staging may affect (a) thoughts and emotions, (b) ability to parent, (c) modes of communication with children, and (d) coping mechanisms to manage the uncertainties of early-stage breast cancer.

Research Questions

I developed two primary research questions and three sub-questions to guide this study. The questions were as follows:

Research Question 1: What coping mechanisms did women use to manage their breast cancer diagnosis, staging of cancer, treatment, and aftermath of their cancer experience?

Sub-question 1: Did the diagnosis of breast cancer and staging affect the manner in which women coped with psychological stress?

Sub-question 2: Did breast cancer treatment affect women's psychosocial functioning (e.g., how they interacted with their children and others)?

Sub-question 3: Did the experience of breast cancer have an impact on women's capacity to manage the uncertainties of survivorship (e.g., recurrence of cancer)?

Research Question 2: Did communication between mothers and their children change on account of mothers' breast cancer diagnosis?

Sub-question 1: Did communication between mothers and their children change prior to the breast cancer diagnosis?

Sub-question 2: Did communication between mothers and their children change during cancer treatment?

Sub-question 3: Did communication between breast cancer survivors and their children change post-treatment?

Purpose of the Study

The purpose of this study was to understand the interrelationship among several variables: cancer diagnosis/staging, psychosocial coping among maternal breast cancer survivors, and patterns of communication. The units of analysis were the effects of early-stage breast cancer diagnosis/staging and treatment on coping mechanisms and communication patterns between mothers and their children.

Conceptual Framework

Both McMaster's theory of family systems communication (Epstein, Bishop, Ryan, Miller, & Keitner, 1993) and Lazarus and Folkman's (1984) transactional model of stress and coping were important when considering the relationship between communication patterns and the diagnosis of early breast cancer. The principle unit of analysis was the mother's emotional reaction to the diagnosis and the cancer staging. Included was the effect of diagnosis and staging on communication patterns between mothers and their children. I examined communication patterns between mothers and their children prior to diagnosis, during treatment, and during remission (i.e., post-treatment). For each of these time periods, I examined the coping mechanisms used by mothers as strategies for maintaining the integrity of their parental role at various stages of breast cancer.

Psychological Coping

I used psychological coping concepts from the seminal works of several experts (Fisher, 2010; Lazarus & Folkman, 1984; Saleeby, 1996) to set boundaries for conceptualizing the variable *coping*. Lazarus and Folkman (1984) found that humans usually regulate psychologically and behaviorally to help manage internal and external demands that exceed one's ability to manage stress. They proposed two types of coping responses to stress: (a)

emotion-focused coping and (b) *problem-focused coping*. Both strategies are available to individuals to implement in stressful situations.

By using emotion-focused coping strategies, people create psychological narratives ("I can do nothing about it" or "I am powerless") from internal emotional states (e.g., fear) and therefore may use *psychological defenses* (e.g., avoidance, fantasy, and minimization) to manage stressful situations. Individuals who use a problem-focused coping strategy, on the other hand, alter internal and external stressors by direct action and are oriented toward learning new skills, seeking support, and identifying new ways of achieving emotional gratification (Cheng, Tsui, & Lam, 2015).

Communication

Communication among cancer survivors, family members, and healthcare teams is an important factor in cancer care (Shields, 2007). According to Surbone et al. (2013), cancer patients have unique communication needs when talking with spouses, children, and family members about their diagnosis, stage, prognosis, and treatment. The McMaster model, an integrated postmodern approach to family systems initiated by Epstein et al. (1993), provides guidelines and a strategy for setting parameters for the meaning and use of effective versus ineffective communication styles and patterns. This model is especially useful for addressing communication barriers among family members dealing with health crises (Evans et al., 1987).

Family system approaches to effective communication emphasize the importance of recognizing the individuality of each family member. While family members share familial conflicts, each member has specific needs that differ from those of other family members; similarly, each member may manage the conflicts differently. Parents should recognize these

differences and structure interpersonal processes, including communication strategies, according to the needs of the child, parent, and family as a whole.

Definition of Terms

Given the nature of this qualitative study, I did not measure concepts of communication and coping quantitatively. The following terms were fully adequate for the descriptive and evaluative categories required for this study.

Affective involvement: According to McMasterian theorists, the degree to which family members as a whole value and demonstrate the interests and activities of family members (Epstein et al., 1993).

Affective responsiveness: According to McMasterian theorists, an individual's ability to respond to others with appropriate feelings (Epstein et al., 1993).

Avoidant communication: A pattern of communication used by individuals to circumvent interpersonal conflict (Epstein et al., 1993).

Avoidant coping: A psychological defense used by individuals to avoid dealing with emotional stressors (Lazarus, 1993).

Emotion-focused coping: A coping strategy used to manage and reduce the emotional effects of distressing situations. Individuals often use emotion-focused coping when they are not able to use self-reflection to manage a high degree of emotional stress. Emotion-focused coping may result in the use of other psychological defenses such as denial, avoidance, and passive aggressiveness (Lazarus, 1993).

Proactive communication: A direct, clear, intentional, and attentional mode of human expression that includes logical sequences of thought, empathy, and expressed emotion (Epstein et al., 1993). Proactive communication involves (a) paying attention to non-verbal messages, (b)

active listening, (c) frequent communication clearly and directly stated, (d) emphasis of the positive (being hopeful), and (e) focus on *I messages* (Surbone et al., 2013).

Proactive coping: The conscious ability and effort to resolve and psychologically manage personal and interpersonal conflicts (Kayser, Sormanti, & Strainchamps, 1999).

Problem-focused coping: A coping strategy to manage stressful situations by use of self-reflection and the ability to plan or problem-solve with minimal use of emotion for psychological regulation (Folkman, Lazarus, Gruen, & De Longis, 1986).

Psychosocial functioning: The ability to interact and negotiate with various systems (individuals, family members, community members, etc.) to meet physical, psychological, and emotional needs (Mills, 2012).

Reactive coping: Intense emotional stress triggers resulting in the inability to manage anxiety by use of self-reflection and the inability to plan or problem-solve (Kupst & Bingen, 2006).

Assumptions

In this study, I assumed that my choice of methodology and design was a "best fit" for the study. I also assumed that a mother's cancer stage may have a significant emotional impact on mothers and may affect communication patterns between mothers and children. A more advanced stage of cancer could result in a mother's need to alter communication patterns and/or interactions based on her conceptualization of time (i.e., time may be limited because of health uncertainty). Further, I assumed that mothers' use of positive/effective communication patterns with their children helps mothers cope better with their experiences of breast cancer. Conversely, I assumed that maladaptive/ineffective communication patterns between mothers and their

children compromise mothers' coping skills. Finally, I assumed that participants shared similar perceptions and worldviews.

Scope and Delimitations

This study included a sample size of 20 breast cancer survivors parenting school-aged and/or adolescent children on Long Island, New York. Participants had a diagnosis of early-stage breast cancer (Stage 0 through Stage IIB) and completed treatment at least one year prior to their participation in this study

A smaller sample size was more manageable, given realistic resource constraints such as time, money, space, and assistance from others. Importantly, this purposive sample size of 20 participants increased the potential for additional time to conduct more in-depth examinations of participant experiences. Additional time with each participant increased the richness of the data.

Study Limitations

The primary limitation of this study was the small sample size of 20 participants, compared to studies in which researchers used larger samples to examine the effects of cancer staging and prognosis on communication and coping.

In addition, this study involved a retrospective process that could influence memory. Therefore, participants may have had a limited recollection or perception of events and interactions with their children. To manage these limitations, I created a context for participants using recall to recollect memories of previous experiences such as the psychological and emotional impact at the time of initial diagnosis, changes in communication patterns with children, and coping strategies used throughout the breast cancer continuum.

Another limitation was that mothers developed an idealization of breast cancer survivorship after one year of their diagnosis, treatment, and recovery. Participants experienced

mild states of psychological and emotional euphoria as a result of recovery and anticipated remission. As a clarifying guide, I provided a context for participants to help them focus and organize thought content from past events and experiences. Finally, the patterns of responses from research participants may or may not have been similar to those in other parts of the United States or globally.

Significance of the Study

The primary significance of this study includes the enhancement of maternal health by helping mothers with early-stage breast cancer to identify coping techniques through effective communication with their children and to improve psychosocial functioning. Effective communication skills may improve psychological states and help mothers cope with the physical symptoms of their illness and the side effects of their cancer treatment (Ares et al., 2014).

The nature, processes, and outcomes may broaden social awareness of the psychosocial needs of children and family members of breast cancer survivors, particularly regarding family communication and coping. Oncology teams can use data from this study to create or enhance policy and protocols for health professionals in various settings in which cancer patients and their family members access services, such as hospitals, outpatient clinics, and community-based mental health services.

Oncology healthcare professionals can also use data from the study to enhance existing services. Oncologists, nurses, and social workers may incorporate similar ideas about communication and coping into their practice. Oncology teams may plan and implement program interventions to address communication barriers and coping strategies at the time of initial diagnosis.

Summary

A chronic and life-threatening illness may pose challenges to mothers' parental identity and confidence in their ability to effectively parent (Molina et al., 2014). Although cancer staging is important for determining a course of treatment and prognosis, mothers must also manage the anxiety that accompanies the uncertainties of their breast cancer stage (Sullivan-Singh, Stanton, & Low, 2015). Furthermore, Sada et al. (2011) maintained that communication is required for psychosocial functioning. The primary feature of a psychosocial experience is the ability to psychologically and emotionally manage the interrelation between individual thoughts and behaviors and social factors (Saleeby, 2009).

Mothers diagnosed with breast cancer face challenges to their emotional and social functioning, especially when parenting young and adolescent children. According to Trevithick (2012), psychosocial functioning means the ability to successfully experience, display, and relate emotional states to the environments and situations in which they occur. Saleeby (2009), and Trevithick (2012) claimed that communication skills and psychosocial skills were correlates to help individuals interact and function in a meaningful context. Sullivan-Singh et al. (2015) argued that psychosocial skills and communication skills are necessary for psychological coping.

Chapter 1 included an overview of this study, in which I outlined the primary components of the research. Chapter 2 includes a review of the literature produced by scholars from several disciplines including maternal medicine, nursing, psychology, and social work, with a shared focus on psychosocial oncology. Furthermore, this chapter includes (a) a discussion of gaps in the literature concerning the coping mechanisms that mothers use to manage emotional and psychological stress related to the uncertainty of a chronic, life-threatening illness and (b) a discussion of the relationship between an early-stage breast cancer diagnosis and breast cancer

staging and mother-child communication patterns. In Chapter 3, I discuss the methodology and research design. In Chapter 4, I report on the findings of the study, and in Chapter 5, I provide analysis/synthesis of the findings and a summary of anticipated and unexpected patterns and themes that emerged from the findings. I conclude Chapter 5 with recommendations and reflections on the study and dissertation process.

Chapter 2: Literature Review

Introduction

The purpose of this study was to examine the relationship among three variables: (a) cancer diagnosis/staging, (b) maternal cancer survivor coping, and (c) communication patterns between breast cancer survivors and their children. I assumed that effective communication strengthens coping and psychosocial functioning, thereby increasing coping outcomes among mothers who are cancer survivors. The National Coalition for Cancer Survivorship (2014) defines *cancer survivorship* as the broad experience of living with, through, and beyond a cancer diagnosis.

The search engines I used to identify relevant studies for this literature review included Walden University's online library, local university libraries, and other online library databases such as AOSW, APOS, ASCO, Google Scholar, MEDLINE, NCBI, ONS, PsycARTICLES, PsycINFO, PubMed.gov, Scorpus, Sociological Abstracts, Social Services Abstracts, Web of Knowledge, and Wiley Online Library. I also reviewed websites from such sources as the American Cancer Society, the Association of Cancer Online Resources, Cancer Care, Disney's Babble, and Mothers with Cancer.

Key terms used in the search included *attachment, cancer survivor, coping, effective communication, expressive coping, health communication, maternal cancer, maternal-child bond, maternal health, nursing oncology, parental bond, psychological resilience, psychosocial functioning, psychosocial oncology, psychosocial resilience, paternal cancer, peer support, social work oncology, parental cancer, psychosocial oncology (psycho-oncology),* and *socio emotional selectivity theory (SST).*

In the first part of this review, I focus on the construct of psychological stress and coping. I define coping categories and mechanisms, identify correlates related to the emotional stress of cancer, and discuss the use of coping mechanisms by survivors to manage the impact of cancer. In the second part of the review, I include an operational definition of communication based on McMaster's theory of family systems communication (Epstein et al., 1993). This involves an understanding of affective communication and affective responses between family members; these factors constitute effective communication within family systems.

I begin the third part of this literature review with the available scholarly research on the psychosocial aspects of the cancer experience, encompassing the experiences of cancer survivors. Understanding the experience of parental cancer sets the context in which to specifically explore the relationship between maternal cancer and effective modes of communication between cancer survivors and family members.

The fourth part includes a review of various research methods and designs (i.e., survey research, case studies, quantitative and qualitative, and mixed methods) commonly used to study the relationships between an individual's cancer diagnosis, treatment, and survivorship and their effects on cancer patients, cancer survivors, and family members.

The fifth part contains a review of conceptual frameworks used in each of the relevant studies. I first discuss frameworks constructed by authors who have investigated the relationship between coping mechanisms and psychosocial adjustment of cancer patients and their children. I then discuss frameworks constructed by authors who have investigated modes of communication between cancer survivors and their children throughout the cancer continuum.

Literature Review Limitation

The literature review included contemporary and relevant investigations to organize and direct a particular research focus. Seminal studies, anecdotal material, and secondary sources were also required to motivate and frame an understanding of the study, specifically the psychosocial aspects of cancer, which encompass health-related communication strategies and psychological coping that pre-dated 2012.

Of importance to this study were landmark studies that included communication and coping as important factors for optimal psychosocial functioning. However, unlike this study, investigators in these previous studies neither considered the effects of different cancer stages on communication patterns between mothers with early-stage breast cancer and their children nor conducted a systematic examination of coping strategies among early-stage maternal breast cancer survivors.

In five of the studies, researchers examined the impact of effective communication on optimal cancer survivor and family member psychosocial functioning (e.g., Al-Zaben, Al-Amoudi, El-deek, & Koenig, 2014; Batenburg & Das, 2014; Campbell-Enns & Woodgate, 2013; Donovan-Kicken et al., 2012; National Breast Cancer Foundation [NBCF], 2015). Investigators found that when people, whether cancer survivors themselves or survivors' family members, openly discussed their cancer experience, anxiety about the disease decreased through the use of these effective communication skills.

In six additional studies, researchers examined the relationship between effective communication and psychosocial functioning of cancer survivors and family members, but also included coping in their conceptual framework (e.g., Campbell-Enns & Woodgate, 2015; Eicher, Matzska, Dubey, & White, 2015; Manne, 2004; Mazzotti, Serrano, Sebastiani, & Marchetti,

2012; Molina et al., 2014; Sullivan-Singh et al., 2015). Furthermore, researchers (e.g., Eicher et al., 2015; Molina et al., 2014; Sullivan-Singh et al., 2015) examined the effects of communication on coping and found that effective communication may be a plausible coping mechanism for psychosocial adjustment among cancer survivors and family members, particularly survivors' children.

Part I: Coping Categories and Coping Mechanisms

Defining Coping Categories and Coping Mechanisms

Unlike *defense mechanisms,* coping is the conscious effort to resolve personal and interpersonal conflicts (Golby, 2014). According to Batenburg and Das (2014), coping involves the skills, abilities, knowledge, and insights that accumulate over time as people struggle to surmount adversity and meet challenges. Coping is an ongoing and developing form of psychological energy and skill used in current struggles (Saleeby, 2009). Early definitions of coping referred to dynamic processes encompassing positive adaptation within the context of significant adversity (Lazarus, 1993).

According to Lazarus and Folkman (1984) in their seminal work on psychological adjustment adaption to stress, a person's coping strategies overlap with their defense mechanisms. Cognitive appraisal occurs when a person is confronted with stress and considers: (a) the threatening nature of the perceived threat and (b) the options or resources available to them to decrease or eradicate the stressor and the anxiety or fear produced by the stress. Lazarus and Folkman (1984) argued that a secondary appraisal occurs simultaneously with the primary appraisal and involves emotions associated with managing the stressor or the stress that it produces.

Proactive coping and/or constructive coping include anticipation regarding how a person will cope with a stressful situation. Maladaptive coping and/or non-coping involve anxious avoidance, escapism (e.g., self-medicating with alcohol, drugs, etc.), and dissociation (e.g., compartmentalization of emotions, thoughts, and memories). Categories of coping include (a) problem-focused coping (e.g., solution-oriented, aimed at removing or reducing the cause of stress through proactive measures), (b) emotion-focused coping (e.g., the emotional responses and/or reactions to stress; especially suited for stressors perceived as uncontrollable), and (c) avoidant-focused coping (e.g., intolerance of negative emotional states).

Implicit within Lazarus and Folkman's concepts were two critical conditions: (a) an exposure to significant threat or severe adversity and (b) the achievement of positive adaptation despite major assaults on the developmental process (Luthar, Cicchetti, & Becker, 2007). Eicher et al. (2015) defined coping in terms of the presence of protective factors (e.g., personal, social, familial, and institutional safety nets), which enable individuals to resist life stress. However, an important component of resilience is the hazardous, adverse, and life-threatening circumstances that resulted in individual vulnerability (e.g., a cancer diagnosis). To calculate an individual's resilience at any moment, the ratio between the presence of protective factors and the presence of deleterious circumstances must be present (Eicher et al., 2015).

Coping with Cancer

According to Sammarco (2009), empirical research and theory development on coping resilience and cancer care have been the domain of pediatric oncology. Psychological coping and psychological resilience may independently contribute to low emotional distress in cancer patients. The relationship among coping, resilience, and emotional distress was also significant in the sub-group of metastatic cancer patients. Psychosocial interventions to enhance coping and

resilience (e.g., effective communication among patients, medical teams, and family members) might provide useful approaches to overcome cancer-related emotional distress.

For all phases of the cancer continuum, constructs of coping and resilience included pre-existing characteristics such as (a) demographics and personal attributes (i.e., optimism and social supports), (b) mechanisms of adaption, such as coping and medical experiences (i.e., positive provider communication), and (c) psychosocial outcomes (i.e., growth and quality of life). The consistent outcome was that promoting resilience and coping is an important factor of patient-family psychosocial cancer care (Eicher et al., 2015).

Maternal oncology researchers have focused primarily on how children and families cope with a cancer crisis (Batenburg & Das, 2014); the sole focus of care and intervention has been on children and families (Giesbers, Verdonck-de Leeuw, van Zuuren, Kleverlaan, & van der Linden, 2010). Researchers in oncology social work appear not to be expanding their knowledge base by critically exploring resiliency, coping, and communication patterns among mothers who are cancer survivors (Batenburg & Das, 2014; Golby, 2014; Lagerdahl et al., 2014; Mazzotti et al., 2012; Molina et al., 2014). In addition, although a considerable number of cancer patients suffer from emotional stress that might have an impact on their quality of life, it remains poorly understood which psychosocial factors contribute to the individual vulnerabilities and emotional distress of cancer patients (Molina et al., 2014).

Society associates various roles and demands with certain points along a woman's lifespan (Sammarco, 2009). In younger women, role expectations usually include expression of spousal relationship, sexuality, childbearing, care of young children, and career development (Molina et al., 2014). In older women, role demands usually involve a transition to retirement while maintaining independence. Older women must adjust to their declining physical function,

cope with the development of chronic illnesses, and manage the loss of a spouse/partner through bereavement (Bookman, 2009). Having constrained financial resources and becoming increasingly frail, older women rely on in-home caregivers such as adult children, grandchildren, ailing spouses/partners, elderly parents, and/or nursing home facilities (Molina et al., 2014).

Sammarco (2003) argued that a breast cancer diagnosis requires women to adjust to the intrusion of a life-threatening disease into their lives and to manage the after-effects of treatment therapies regardless of age, ethnicity, or stage of life. Breast cancer intensifies emotional stress by threatening life and functional status and often impacts the multiple role demands that come with a woman's particular psychosocial life stage. This situation clearly affects the quality of life (QOL) of both younger and older women in diverse ways that often continue for years beyond the completion of treatment (Sammarco, 2009).

Molina et al. (2014) found that women using effective communication skills as a method of expressive coping reported higher quality of life during their cancer diagnosis because they were more likely to express positive emotions, reframe the experience positively, and cultivate a sense of peace and meaning in their lives. These researchers also concluded that interventions promoting a sense of purpose in one's life and facilitating the expression of positive emotions might prove beneficial, especially for women who report coping strategies and high levels of resilience and coping (Bookman 2009).

Communication

Defining Communication

Communication is the exchange of verbal and non-verbal information between people. Importantly, communication is required as a function of family systems and psychosocial functioning (Ionescu, 2014). Affective communication and instrumental communication are the

primary modes of communication. Affective communication is the expression of feelings about ourselves, others, and things in general. Instrumental communication is outcome-oriented and problem-solution focused. Effective communication is clearly expressed, direct, and intentional. Ineffective communication is indirect, masked, and often based on assumptions (Donovan-Kicken et al., 2012).

The ability to express (verbally or non-verbally), receive, and exchange ideas, information, messages, or signals is important to human relationships. Historically, family communication experts and theorists (Epstein, Bishop, & Levin, 1978) used insights from family systems theory and the McMaster Model of Family Functioning to construct and explain the relevance of communication practices that begin within the structure of family life. To understand how patterns of communication occur within and between family members, Epstein et al. (1993) presented two important facets of effective communication: (a) affective communication and (b) affective responses. Affective communication is the process through which family members express themselves emotionally to one another. Affective responses are the emotional responses to situations.

According to Epstein et al. (1993), effective communication encompasses not only the exchange of information but also an understanding of the emotion behind the information. This type of communication improves relationships by strengthening bonds with others and by improving teamwork, decision-making, and problem-solving within families. Through effective communication, an individual can communicate negative, even difficult, messages without creating conflict or compromising trust. Effective communication includes non-verbal communication, attentive listening, and the capacity to recognize and understand one's emotions and the emotions of others (Surbone et al., 2013).

Relationship Between Communication and Cancer

According to the National Cancer Institute (2015a)**,** effective communication between and among cancer survivors, family caregivers, and healthcare teams helps improve a survivor's sense of well-being and quality of life. Parents with cancer and their children can use effective communication as a method to defuse high-anxiety states associated with the uncertainty of the cancer experience. Communicating about concerns and decision-making processes is important during all phases of cancer treatment, supportive care, and survivorship. Additionally, the dynamics of a thriving relationship between cancer survivors and their loved ones require consistent patterns of effective communication (Surbone et al., 2013).

The psychosocial oncology literature consists largely of studies conducted by researchers in nursing oncology. Investigators from social work and nursing oncology have focused primarily on the psychosocial needs of spouses and caregivers, children, and families of adult cancer survivors. Flahault and Sultant (2010) also conducted psychosocial studies in pediatric oncology concerning the role of effective communication and coping between parental figures, siblings, and family members. Researchers have found that the deleterious emotional effects of cancer on a family system are significant and often dramatically manifest in daily life changes for children of cancer patients. Furthermore, Clemmens (2009) found that children of cancer patients frequently spend more of their free time at home and report feelings of helplessness, loneliness, and uncertainty.

Numerous investigators (Flahault & Sultant, 2010; Ganzendam-Donofrio et al., 2010; Wong et al., 2010) concluded that stress manifests itself in elevated levels of anxiety and depression and decreased self-esteem. These findings are important for medical professionals who attempt to address the needs of the entire family affected by cancer. According to Ares et

al. (2014), few researchers have explored parental perceptions of parenting as a coping mechanism throughout the cancer continuum. Similarly, researchers have not addressed the psychosocial needs of mothers who have been in cancer treatment and/or survived cancer (Golby, 2014). Furthermore, investigators have primarily only explored the psychosocial dimensions of spouse-child-family issues of breast cancer patients (Ares et al., 2014).

The Psychosocial Aspects of Cancer

In a survey of medical oncology literature, the medical and genetic aspects of cancer include the diagnosis, treatment, and prevention of the disease. The specialty of psychosocial oncology, or psycho-oncology, treats a range of human needs in order to enhance the quality of life for people affected by cancer, both cancer patients and their loved ones. This specialty specifically examines the emotional, psychological, social, and spiritual effects of cancer (Stanton et al., 2000).

The term *psychosocial* refers to a person's ability to adjust the mind and body to a social environment (Trevithick, 2012). Scholars stress the importance of both internal and external factors in relation to an individual's ability to cope with the everyday stresses of living (Raingruber, 2011; Saleeby, 2009; Trevithick, 2012; Woods & Hollis, 1999). The term *psychosocial* incorporates the internal psychological and emotional aspects of life, as well as the external social and relational dynamics of a person's life.

Psychosocial interventions include the identification and utilization of an individual's personality strengths and environmental resources in order to develop and enhance effective personal and interpersonal functioning (Woods & Hollis, 1999). Communication strategies and supportive interpersonal experiences are factors in optimizing psychosocial functions and mental health for cancer survivors and their family members (Epstein et al., 1993). These psychosocial

interventions are valuable adjuncts to physical treatment for individuals diagnosed with chronic, life-threatening illnesses like cancer (Raingruber, 2011).

The psychosocial aspects of cancer care must include interventions that focus on the informational and communication needs of cancer survivors (Sullivan-Singh et al., 2015). Facilitating emotional expression helps to modulate distress and enhance coping abilities. The use of psychosocial interventions can minimize health-related anxiety, treat depression, support cancer patients throughout the course of their diagnosis and recovery, and improve quality of life (Tao et al., 2015).

According to Kupst and Bingen (2006), parents and their children frequently reported psychosocial cancer-related stressors (e.g., increased anxiety and depression). Investigators found disruption in social, occupational, and familial roles. While most children and their families successfully adapted to parental cancer diagnosis and treatment, one-quarter to one-third of children exhibited considerable challenges during this process (Hilderbrand, Alderfer, Deatrick, & Marsac, 2011). A significant sub-set of children who had a parent undergoing cancer treatment experienced persistent cancer-related distress, including increased symptoms of anxiety, irritability, depression, and post-traumatic stress (Al-Zaben et al., 2014).

Relationship Between Coping and Communication

Researchers from three central areas (psychosocial oncology, social work oncology, and nursing oncology) explored themes of parenting, cancer, and coping. Researchers within maternal oncology primarily focused on those affected by breast cancer, but have recently expanded their view to cover other gynecological cancers (Fobair et al., 2009). Investigators also explored the theme of helping spouses and children dealing with parental cancer to cope.

A primary focus in maternal oncology is breastfeeding (Batenburg & Das, 2014), with a specific focus on the emotional status of pre- and post-mastectomy mothers and maternal-child attachment (Molina et al., 2014). Ongoing research includes an exploration of the psychosocial aspects of end-stage cancer, as well as end-of-life and palliative care for both children and adults. However, few studies are about early-stage cancer and women's experiences from a maternal oncology perspective (Osborn, 2007).

The trend in oncological and maternal health has focused on the impact of mothers' breast cancer on their children (see Flahault & Sultant, 2010; Osborn 2007). Maternal health, particularly maternal oncology, seems to be lacking contemporary data addressing the psychosocial needs of mothers with breast cancer (Ares et al., 2014).Specifically, researchers (see Clemmens, 2009; Giesbers et al., 2010) have continued to focus on how children cope with their mother's maternal breast cancer. For example, *avoidant coping* in childhood can be a response to a traumatic event or series of events. Avoidant coping repeatedly appears as a risk factor for long-term mental health complications, including stress symptoms related to post-traumatic stress (Shapiro, Kaplow, Amaya-Jackson, & Dodge, 2012). Children and adolescents are often reluctant to disclose any difficulties in their lives, cancer-related or otherwise, to their ill parent, so as not to burden them. Investigators (see Foran-Tuller et al., 2012) appear to remain focused primarily on the needs of the children and their adjustment to maternal cancer.

Previous research on the impact of parental cancer, particularly maternal cancer, reflected a significant disposition to internalizing and externalizing problems in the children of cancer patients (Flahaut & Sultan, 2010; Gazendam-Donofrio et al., 2010; Huizinga et al., 2011). Therefore, given the large numbers of youth affected by maternal cancer and the impact of maternal cancer on children's mental health, an understanding of how maternal cancer affects

children is essential in order to provide appropriate interventions to growing population (Huizinga et al., 2011).

While youth affected by maternal cancer might be able to express their thoughts and feelings to non-parental figures, they often believe that no one can relate to or understand their situation. This loneliness further promotes avoidant coping strategies (Gazendam-Donofrio, 2010). The uncertainty of a cancer diagnosis complicates perceptions of the situation and affects childhood coping. The prognosis within the first year of a cancer diagnosis is always uncertain, and even if a parent reassures a child of a good prognosis, children often assume the worst. They believe that a parent's death might be imminent, despite the relatively low likelihood of such an event occurring.

Expressive Coping and Psychosocial Adjustment

The mental health implications of parental cancer become especially notable when parents are unaware that their children are having emotional difficulties with their diagnosis (Welch, Wadsworth, & Compas, 1996). This exclusion often leaves the children of cancer patients feeling misunderstood (Clemmens, 2009).

To decrease these feelings, parents can use the skills of expressive coping, a form of effective communication. Open communication within families has been found to foster expressive coping, also known as emotion-focused coping (Clemmens, 2009). Expressive coping, unlike a focus on problem-solving, involves efforts to alter or eliminate the problem. This type of coping provides a way of regulating the negative emotional consequences of a stressor by processing and talking about how one feels, limiting time spent on negative narratives, and creating a positive perspective.

According to a study conducted by Fisher (2010), a woman's connection with her family, especially her mother, enhanced coping. Women described the mother–daughter relationship as a significant potential source of support. Furthermore, the women's mother-daughter bond was a significant part of their experience because it allowed for expressive coping. However, although family communication functioned both adaptively and maladaptively in women's adjustment to cancer, health professionals generally do not provide families with guidance on how to communicate adjustment concerns in a healthy manner.

Fisher (2010) argued that these findings regarding effective communication and expressive coping can extend practical and theoretical knowledge of family communication, cancer, aging, and health. Regardless of age, women diagnosed with stage III or IV breast cancer preferred family communication more than women diagnosed with stage I or II breast cancer. These findings enhanced the existing literature in health communication by expanding the theoretical understanding of the role of family communication within the context of cancer. Furthermore, human development was found to affect women's open, avoidant, and support communicative needs when adjusting to breast cancer; Fisher (2010) highlighted the need for experts to appreciate the context in which family communication functioned and adjusted adaptively.

The symbolic processes of communication link how people experience health and wellness, physical and mental illnesses, and their bodies (Shields, 2007). Consistently open and direct communication patterns among family members, friends, co-workers, physicians, nurses, and others influence well-being at individual and group levels. However, health conditions also have implications for communicative practices (Donovan-Kicken et al., 2010). Patients often avoid communicating about cancer, but such avoidance is likely to have negative psychological

health consequences for those patients. There is a need for scholars to further examine the connection between topic avoidance, psychological well-being, and psychosocial adjustment.

A diagnosis of cancer is devastating and life-altering. Initially, many diagnosed women cope with their diagnosis alone. However, experts find that a patient's family interactions are critical to her adjustment and well-being (Al Zaben et al., 2014; Mazzotti et al., 2012; Sullivan-Singh et. al, 2015). Cancer can also be a threat to the security of a mother's parental role by compromising her ability to optimally take care of her children. Furthermore, diagnosis and treatment of cancer can exacerbate a mother's attempts to keep her family unified (Mazzotti et al., 2012).

Huizinga et al. (2011) examined the relationship between avoidant coping and anxiety-related mental health outcomes in children of recently diagnosed female breast cancer patients. They found that children and adolescents coping with parental cancer are at a higher risk for mental health complications, with avoidant coping exacerbating these symptoms in children dealing with any number of life stressors.

Expressive coping is a protective mechanism in other young, vulnerable, groups including bereaved children and young sexual abuse victims (Kaplow, Dodge, Amaya-Jackson, & Saxe, 2005). Few studies have focused on children facing maternal cancer and the interplay of coping mechanisms and mental health in this particular population (Mazzotti et al., 2012). Results of this study may provide preliminary information to (a) help identify protective factors and (b) potentially serve as important targets for intervention for the millions of children affected by maternal cancer.

Children's self-reports of what they found to be most helpful when faced with their mother's cancer diagnosis included: (a) Perceived Support, (b) Opportunity to Express Oneself,

(c) Information Gathering, and (4) Reassurance/Perception of Prognosis (Al-Zaben et al., 2014). This qualitative data provided a firsthand account of what children believed to be helpful. Clinicians can easily integrate many of these concepts and processes into their intervention efforts with this population. These conceptual categories are consistent with other studies (Davey et al., 2011; Gazendam-Donofrio et al., 2010) that find similar positive adolescent and child coping strategies in the face of parental illness. All four categories related to parent-child communication, which is one of the most important predictors of child functioning when a parent has cancer (Huizinga et al., 2011).

Osborn (2007) found that mothers with a cancer diagnosis were more prone to discuss their diagnosis with their children once they had clarity concerning prognosis and treatment. Mothers know that communication is an important variable for providing social support to children within the family. Later, Mazzotti et al. (2012) found that a mother's desire and need for open communication with her child might be a factor in her treatment and recovery process. Mothers who are oriented toward self-expression use open communication as a means to cope with anxiety. These mothers appeared less preoccupied about their cancer diagnosis and better able to maintain a focus on treatment and recovery (Huizinga et al., 2011).

Campbell-Enns and Woodgate (2015) and Molina et al. (2014) found that mothers often feel threatened by their diagnosis, as it affected the stability of their parental role. Mothers believe that their diagnosis could undermine their ability to take care of their children and keep the family together. Some mothers tend to handle their disease as if it were a temporary event. From the moment of diagnosis, the life of a mother and that of her children and family undergoes important changes in both the short and the long run; these changes form the basis of other strategies for coping (Mazzotti et al., 2012).

Review of Methodologies

Coping with Cancer

Researchers (Eicher et al., 2015; Mann et al., 2014; Molina et al., 2014; Sullivan-Singh et al., 2015) have investigated the linkages among an individual's experience with cancer, communication, and psychological resilience brought about by different coping mechanisms. Although the approaches to data collection differ, researchers have found significant correlations among effective communication, coping, and resilience among cancer patients, caregivers, and other support systems.

Eicher et al. (2015) argued that limited knowledge exists among scholars and professionals about the relationship between effective communication strategies and emotional health among adult cancer survivors. The authors conducted an integrative literature review, including search engines with CINAHL, PubMed, and PsycINFO databases and with Full-text. The study also included peer-reviewed articles published since 2003. The authors retrieved 252 articles in total, with summarized quantitative research yielding 29 eligible studies. They evaluated and synthesized 11 articles, extracted and tabulated data, and synthesized the results. The authors found that the link between modes of communication and improved health outcomes was an especially under-researched phenomenon.

Mann et al. (2014) conducted a cross-sectional quantitative study to examine coping strategies among and between survivors of gynecological cancer. The sample included 281 women in a randomized clinical trial. The mean age of participants was 55 years of age. Participants completed measures of resilience from four categories: (a) expression of positive emotion, (b) positive reappraisal, (c) cultivation of a sense of meaning and peace, and (d) quality of life.

Using multiple mediation and univariate analyses, researchers have found that greater coping and resilience related to a higher quality of life among cancer survivors (Molina et al., 2014). The potential for creating effective coping mechanisms was associated with women's descriptions of cultivating a sense of meaning, inner peace, and quality of life. Each of these positive coping skills translates to resilience; furthermore, the authors found that women often associated coping with communication (Molina et al., 2014).

Molina et al. (2014) also examined the relationship between coping, resilience, and emotional stress in cancer patients. One hundred fifty-two cancer patients consecutively hospitalized for their treatments at the Seoul St. Mary's Hospital completed the Connor–Davidson Resiliency Scale and Hospital Anxiety Depression Scale to measure resilience and emotional distress. The authors defined the variables expected to change over time and the patients' experiences of coping following a new diagnosis of cancer.

Molina et al. (2014) examined the differences between older and younger breast cancer survivors. Of interest were the participants' perceived social support, uncertainty related to a life-threatening illness, quality of life (QOL), and selected demographic variables. The authors examined these variables to understand their relationship to coping strategies, resilience, and QOL. For this study, researchers recruited 163 older and 129 younger breast cancer survivors.

Participants completed the Mishel Uncertainty in Illness Scale Community Form, Quality of Life Index-Cancer Version III, and the Social Support Questionnaire (Molina et al., 2014). The authors used quantitative measures to test for significant differences occurring between younger and older cohorts in nurse social support sub-scales. Instruments used included: (a) psychological/emotional QOL sub-scales, (b) spouse and socioeconomic sub-scales, and (c) total social support. The authors also included religion and spirituality, as well as (a) additional

illnesses, (b) age, (c) health uncertainty, (d) mastectomy, (e) medical treatment (i.e., chemotherapy and/or radiation therapy), and (f) social support, as predictors of QOL.

Sullivan-Singh et al. (2015) used a mixed method design to examine perceptions of life goals between two groups. The first group included 113 women with metastatic breast cancer and the second included 50 similarly aged women without a cancer diagnosis. Researchers focused on how a future foreshortened by terminal illness affected emotional stimuli and motivation while under greater time limits. They also investigated the degree of socioemotional selectivity between women with late stage or metastatic breast cancer and their peers without a cancer diagnosis.

The first phase of the study included open-ended interview questions about participants' views of life goals (Sullivan-Singh et al., 2015). Researchers used the Impact of Event Scale and Striving List to assess the socioemotional selectivity between the two groups. In the second phase of the study, researchers followed the first group of women over a three-month period and reassessed the women's life goals and psychological adjustment through an additional questionnaire.

The authors (Sullivan-Singh et al., 2015) found that participants from the first group were not motivated by intrusive thoughts about cancer or a shortened life. Participants often rationalized limited time perceptions by focusing on important relationships and emotional bonding experiences. Participants in the first group also did not view life goals as time limited, but as key factors for neutralizing the emotional turmoil and existential angst associated with notions of a limited lifespan.

Relevance of Communication Within the Cancer Experience

Batenburg and Das (2014) and other scholars (Al-Zaben et al., 2014; Campbell-Enns & Woodgate, 2013; Donovan-Kicken et al., 2012; Mazzotti et al. 2012; NCI, 2015a) investigated the relationship between modes of communication, psychosocial coping, and cancer survivorship. The studies differ in methodological approach, selection of the population, sample size, and analyses. However, the authors all found links between effective communication, optimal psychosocial functioning, and coping of cancer survivors.

Batenburg and Das (2014) argued that oncology professionals did not understand individual coping strategies among cancer survivors. Furthermore, few researchers have examined how cancer survivors cope with cancer-related emotions. Using a quantitative, cross-sectional design, Batenburg and Das (2014) examined the relationship between communication, and cognitive and emotional expression with 184 breast cancer survivors from an online support group.

They asked research participants in a peer-led, online support community to complete a questionnaire assessing how they cope with emotions and their thoughts regarding their illness. The first section of the structured questionnaire included questions about (a) cognitive avoidance, (b) emotional processing, and (c) expression. The second section included questions about psychological well-being, such as signs of depression, breast cancer-related concerns, and emotional well-being. The sample participants (n=163) who completed and submitted the questionnaire unanimously voiced a need to discuss their cancer experience and expressed the benefits of doing so. Investigators found that online interaction helped improve participants' mood and emotional well-being. Participants reported decreased cognitive avoidance of breast cancer and increased emotional coping and psychosocial functioning due to communication.

Donovan-Kicken et al. (2012) conducted a qualitative grounded study to better understand the meaning that breast cancer survivors attribute to their cancer experience, including how they benefitted from speaking with others about their cancer experience. The sample population comprised 40 breast cancer survivors from a focus group. Investigators used an interview guide with semi-structured interview questions to examine modes of communication as coping strategies among cancer survivors. Interviews were audio-recorded. Of the 40 interviews, 37 participants reported that open communication about cancer significantly helped them cope with the uncertainty of their diagnosis. Thirty of the 40 participants also stated that attempts to manage communication about the cancer experience were challenged by unpredictable and unfavorable reactions.

Researchers from the National Cancer Institute (2015a) conducted a qualitative study to investigate, compare, and contrast modes and content of communication among cancer survivors. Investigators recruited 40 individuals who were at least 18 years of age and who had been diagnosed with cancer at any point. In recruiting survivors, investigators adhered to NCI's definition, which regards an individual as a survivor from the day of diagnosis onward. Oncology experts agree with NCI's definition (ACS, 2015).

A combined gender sample (n = 40, with 28 women and 12 men) with ages ranging i from 21 to 74 years old participated in this study (NCI, 2015a). Included were 13 different types of cancer, with breast cancer and lymphoma being the most common. Length of time since participants' cancer diagnoses ranged from one to eleven years. The study included an initial target of four to five focus groups of six to eight participants.

Investigators conducted nine total focus-group interviews. During all interview sessions, researchers followed a semi-structured interview guide to inquire about survivors' experiences

with communication and cancer. The interview guide allowed researchers to probe for additional information while still allowing participants to generate their narratives (NCI, 2015a).

Specific topics covered in the interviews included how to talk to others about their cancer, their management of illness information, challenges and benefits of communication, and advice that they had received or would offer about communication. All interviews were audio-recorded and investigators maintained theoretical memos throughout conceptual development. Furthermore, researchers used member checking and peer debriefing to establish validity (NCI, 2015a).

Mazzotti et al. (2012) used a multiple case study design to examine the function of motherhood as a factor for effective communication and coping among breast cancer survivors and their children. Due to the qualitative design, researchers gained an understanding of the meaning that women assigned to their experiences of breast cancer and its impact on communication with their children.

The sample size included eight women (26 to 58 years of age, with an average age of 46 years old) from an outpatient clinic in Rome, Italy. Cancer survivorship among participants ranged from 1 to 20 years. Investigators used an interview guide with semi-structured interview questions. Audio-taped, face-to-face interviews occurred between November 2010 and January 2011. During the interviews, women shared their stories of breast cancer and discussed the meaning they attached to the illness. Additionally, participants offered insights into the impact their breast cancer had on themselves, their children, and other family members (Mazzotti et al., 2012). According to Mazzotti et al. (2012), the purpose of the study was to encourage participants to speak about their concerns regarding their experience of cancer and to introduce new ideas to the researchers. For this purpose, the first question of the interview was open-

ended: “Can you describe for me what it was like when first diagnosed with cancer?" This kind of inquiry initiated a narrative reconstruction of women’s experiences and allowed participants to openly discuss issues of concern, rather than focusing on what the researcher considered important.

Mazzotti et al. (2012) also used a narrative approach to explore the difficulties and challenges in communicating about cancer, as well as the important strategies for managing communication. The underlying assumption of the narrative research was that the respondent’s construction of a story mirrored the primary way in which human beings make sense of their experiences. The function of identifying narrative segments and their representations was not a technical operation but a method of content analysis.

Participants’ responses guided the direction of the interview process (Mazzotti et al., 2012). Interview questions were followed by clarifying questions which allowed for elaboration and exploration of topics raised spontaneously. A period of debriefing occurred at the end of each interview to discuss any feelings that the participant might have experienced during the session. The authors initially transcribed all interviews verbatim in Italian; a professional translator then translated excerpts into English.

Campbell-Enns and Woodgate (2015) conducted an integrative literature review by systematically reviewing published and unpublished studies of female breast cancer survivors across their lifespan. The authors examined literature from several sources (MEDLINE, CINAHL, PsychINFO, SCOPUS, EMBASE, Web of Science, Google Scholar, and ProQuest databases). Studies included women with various stages of breast cancer, except for those with a recurrence of cancer. The researchers compared age with psychosocial issues across women’s lifespan, from younger to older. Representative samples were taken from all geographical

regions and from all cancer care settings - inpatient, ambulatory, primary health care, and home care. Importantly, the researchers included effective communication as an aspect of psychosocial coping and relevancy to quality of life.

Campbell-Enns and Woodgate (2015) found that dissimilarities existed between the experiences of women with breast cancer recurrence and those first diagnosed and treated. Mothers throughout the cancer continuum use their diagnosis and prognosis to construct rationales for communication and decision-making. A diagnosis of cancer evokes an emotional urgency in mothers that affects time perception. Furthermore, factors of health uncertainty and the possibility of a shortened life are conditions through which mothers create meaningful narratives about parenting and maintaining the parent-child bond.

Al-Zaben et al. (2014) conducted a qualitative exploratory study to examine maternal perceptions of the impact of informing children about their breast cancer diagnosis.The criteria for the study were: (a) diagnosis of stage I-III breast cancer, preferably within the past 12 months) and (b) having children ages 5 to 16 years who are attending school. Investigators contacted women who met the inclusion criteria to set up an appointment at a local cancer center. A convenience sample included 28 women, ages 35 years to 60 years old. The instrument used to gather the data was a 39-item, close-ended questionnaire conducted at the Al-Amoudi Breast Cancer Center of Excellence, King Abdulaziz University, Jeddah, Saudi Arabia (Al-Zaben et al., 2014). Each interview took approximately 45–60 minutes with additional time to discuss answers, if needed. The study focused on the relationship between demographic characteristics, attitudes of mothers regarding informing their children of the cancer diagnosis, the way in which mothers communicated this information to their children, maternal perceptions of how the diagnosis affected their children's attitude toward them, and the effect on children’s

school performance. The majority of mothers (70%) informed their children about the cancer diagnosis. Sixty-one percent of participants also explained the treatment process to their children.

Review of Conceptual Frameworks

Psychological and Emotional Coping

In their review of cancer survivorship and coping literature, Eicher et al. (2015) used theories of resilience and coping to frame a theoretical analysis and problem-identification approach in order to (a) describe current theoretical perspectives on the concept of coping and resilience, (b) summarize quantitative research on coping and resilience in adult cancer care, and (c) identify implications for nursing oncology. The authors argued that empirical research and theory development on coping has been primarily the domain of pediatric cancer settings. According to the authors, coping with cancer involves a psychological process of facing adversity related to the uncertainties of chronic and life-threatening illness. Their conceptualization of the process involves the premise that coping is a key factor in resilience among cancer survivors. Furthermore, they discuss the seminal study conducted by Tusaie & Dyer (2003), which finds that strong social bonding was an important aspect of coping, especially when faced with a chronic or life-threatening illness.

Eicher et al. (2015) used the theory of resilience to develop a conceptualization of the relationship between positive social interactions, effective communication strategies, and coping. The authors found that coping strategies were precursors to resilience. In their systematic review of the literature (CINAHL, PsycINFO, and PubMed databases), coping remained an important, yet a poorly understood, issue in adult cancer care. Thus, according to Eicher et al. (2015), researchers must prudently define a conceptual framework for developing nursing or oncology

social work interventions aimed at promoting an understanding of coping among cancer survivors.

Mann et al. (2014) used theories of positive communication, coping, resilience, and psychological adaption to conceptualize how women diagnosed with gynecological cancer might improve their coping mechanisms. The authors developed a paradigm from a theoretical understanding that women tended to discuss their lived experiences through positive emotions. Expressing positive emotions through positive reframing of the cancer experience might significantly improve coping. Furthermore, understanding the relationship between psychological adaptation and coping laid the foundation for examining how open communication strategies may help cancer survivors cultivate a sense of peace and meaning in life.

Molina et al. (2014) used theories of coping and resilience to conceptualize an understanding of coping strategies and resilience throughout the cancer continuum. The authors found that a majority of researchers focused on resilience within the domain of treatment but reported little on coping strategies among cancer survivors. The authors aimed to expand on the concepts of coping and resilience as essential components to survivorship. They identified baseline coping characteristics such as optimism and hope as being present throughout the majority of the stages of the cancer continuum.

As part of this conceptualization, Molina et al. (2014) synthesized the literature and integrated research about the effects of coping strategies on resilience and positive psychological outcomes. The review provided important information to consider at each stage of the cancer continuum and offered healthcare providers and researchers with different aspects of coping among cancer survivors; this information can be integrated into oncology practice.

Communication

Researchers from the National Cancer Institute (2015a) used the theory of communication work and psychosocial functioning to conceptualize an understanding of how cancer survivors manage the social aspects of their cancer experience. Researchers constructed a model for understanding how cancer patients use communication work (strategies) as a means of managing personal and psychosocial aspects of their cancer experience, whether at home with family, socializing with peers, or in a work environment. Some prominent themes emerged, characterizing communication work as: (a) demanding and effortful, (b) a responsibility or obligation sometimes shared with significant others in a division of communicative labor, and (c) anticipatory by preparing and planning for conversations (NCI, 2015a). The conceptual framework used was the relationship between management of cancer, communication work, and coping.

Batenburg and Das (2014) used theories of health communication and psychological coping for a cross-sectional study among breast cancer survivors from an online support group. The authors theorized that cancer survivors may benefit psychologically and emotionally from online peer-to-peer support communities. They focused on explaining why and when online support communities were beneficial for cancer patients.

Previous researchers had not considered differences in individual coping, despite the fact that patients had different methods with which to manage cancer-related emotions. Batenburg and Das (2014) predicted that the effects of online support group participation would somewhat depend on a cancer survivor's ability to cope with thoughts and emotions concerning their illness. They included an investigation of several variables among online participants: cancer type, cancer stage, prognosis, and coping strategies.

Sullivan-Singh et al. (2015) used lifespan theory and a theory of socioemotional selectivity to conceptualize a relationship between perceptions of limited time and psychological motivation. Perceptions of limited time for those living with a life-threatening illness becomes a factor in an individual's attention to the present moment. Those facing limited time were found to choose emotionally meaningful relationships and emphasize the qualities of effective communication and expressive emotion.

Donovan-Kicken et al. (2012) used trajectories of illness and health communication to broaden the understanding of how cancer survivors discussed their cancer experience with others. The authors determined the process by which cancer survivors used labor and resources in managing dialogue during emotionally stressful periods in their lives. Interpersonal communication during the cancer continuum was an important factor in coping for both cancer patients and their family members.

Mazzotti et al. (2012) used communication theory, particularly communication management, to determine whether mothers with breast cancer may adopt dysfunctional and paradoxical communication strategies when communicating with their children about their health status. The investigators theorized that some mothers might experience their cancer diagnosis as catastrophic, while others might handle it as if it were a temporary situation. These strategies imply emotional detachment from their children in order to protect them from cancer-related emotional distress. Their understanding of the process highlighted the relationship between a mother's diagnosis of breast cancer, effective communication patterns between mother and child, and coping.

Campbell-Enns and Woodgate (2015) used lifespan theory and theories of coping and communication to understand psychosocial functioning within the context of health uncertainty.

Theoretical assumptions included that (a) the condition of a mother's life creates a context in which she makes meaningful decisions and (b) mothers diagnosed with breast cancer make decisions based on a host of factors specific to their diagnosis, which impacts psychosocial functioning, especially parenting. The findings highlighted the relationship the effects of maternal breast cancer on psychosocial coping and communication processes between mothers and their children.

Campbell-Enns and Woodgate (2015) theorized that regardless of age, cancer stage, and prognosis, the rearing of young children may be a factor in psychological and emotional distress. A mother's perception of her parental role might be a source of psychosocial stress and might affect coping strategies and quality of life. However, in a recent study, these investigators found that mothers with a good prognosis identified parenting as a useful distraction to help them cope with the uncertainty of cancer.

Al-Zaben et al. (2014) used the psychological relational theory of intersubjectivity to explore the perceptions of mothers who informed their children of their breast cancer diagnosis. Theoretically, the impact of a mother's breast cancer diagnosis and a mother's perceptions about her children's knowledge of her diagnosis influenced the children's psychosocial functioning. Mothers, regardless of whether or not they share their diagnoses with their children, might project onto their children thoughts and feelings about breast cancer, thus possibly hindering children from expressing their own thoughts and feelings.

Summary

A common theme found throughout the literature review is that the cancer experience profoundly affects patients' lives, as well as the lives of their caregivers and families (Waters & Porter, 2014). The specific focus of these studies prior to 2012 was how cancer affects

psychosocial functioning and coping, whether in individual cancer survivors or family systems. Scholars (see Ganz et al., 1996; Schag et al., 1993; Taylor et al., 1985) ascertained from secondary sources that psychosocial functioning is the ability to internally organize and respond to inherent need to (a) interrelate with others and (b) foster and maintain relationships for survival. Experts found that psychosocial functioning is an important component of emotional health and promotes the ability to cope. Historically, scholars defined coping as the ability to manage the adversities of life (Lazarus & Folkman, 1984).

Within the context of health adversity or cancer, researchers (Fisher, 2010; Sada et al., 2011; Sammarco, 2009; Shields, 2007) unanimously found that communication among cancer survivors necessitated optimal psychosocial functioning. Investigators found that cancer survivors identify open and direct communication as an effective method for decreasing health-related stress and social anxiety. Whether it be through an online support group, work environment, medical setting, or in the home, the opportunity to discuss the cancer experience was psychologically, emotionally, and socially beneficial to cancer survivors and others.

Historically, scholars of family systems communication (e.g., Epstein et al, 1978) defined communication as the mutual exchange of ideas, thoughts, and feelings used to create and share meaning. Communication is an important mechanism for establishing and maintaining positive relationships between parents and their children. Parenting skills involve various methods of communication; however, when a mother faces a life-threatening, chronic illness (i.e., breast cancer), it may affect communication patterns between her and her children. Importantly, the cancer experience is part of her lived experience and affects the mother-child relationship.

Experts (Ares et al., 2014; Campbell-Enns and Woodgate, 2013; Eicher et al., 2015) in the disciplines of nursing and social work oncology have recently broadened their scope of

inquiry into the relationship between motherhood and cancer. Importantly, they have shifted focus from the psychosocial needs of children and family to include mothers' own experiences. Researchers (Al-Zaban et al., 2014; Ares et al., 2014; Lagerdahl et al., 2014; Levin et al., 2010; Molina et al., 2014) have found that open and direct communication with children and family about diagnosis, prognosis, and treatment are part of the recovery and survivorship process. Maternal cancer survivors, specifically breast cancer survivors, identified direct and open communication as an important strategy for coping with the uncertainty of cancer, regardless of their prognosis.

Conclusion

Gaps remain in the literature concerning the role of motherhood as a factor in mediating stress related to cancer. Current psychosocial oncology literature does not address mothers' use of the maternal role to cope or motherhood's role as a factor in coping. While attention on maternal cancer has increased, researchers have often only considered how mothers' diagnoses of cancer affects their children, caregivers, and family members (Molina et al., 2014).

Oncological and maternal health literature includes limited psychosocial dimensions regarding motherhood and cancer. There has been little, if any, systematic study of how mothers (a) manage the emotional effects of breast cancer staging and (b) use cancer staging as a mediating factor for constructing effective communication patterns between themselves and their children. Although researchers have explored coping strategies among cancer patients, caregivers, children, and family members, few researchers have examined coping mechanisms among and between early-stage breast cancer survivors.

Chapter 3 will include a discussion of the methodology I used to investigate the psychosocial factors that could shape the experiences of mothers surviving early-stage breast

cancer. This study's chosen research design encompassed the relationship between maternal breast cancer and cancer staging as mediating factors for communication and coping. More specifically, the methodology included a strategy for examining the impact of mothers' breast cancer stage on communication patterns with their children and on coping strategies they may use to manage the uncertainty of their health status.

Chapter 3: Research Method

Introduction

Regardless of stage and prognosis, cancer affects the psychological, emotional, and social lives of cancer patients, as well as those of their family members (Batenburg & Das, 2014). The primary purpose of this qualitative, inductive multiple case study was to understand the interrelationship among several variables including cancer staging, effective communication, and psychosocial coping among maternal breast cancer survivors. The units of analysis were the communication patterns between mothers and their children.

Categorical variables of this study included the independent variable, which was cancer staging among maternal cancer survivors. This study also included three dependent variables, specifically how cancer staging affected maternal (a) emotional status, (b) communication patterns with children, and (c) coping mechanisms. In the following sections, I offer descriptions of the method used to carry out this study.

This chapter includes a discussion of the research design and rationale, the research questions, and a description of the qualitative research paradigm and multiple case study design that I used. The study included maternal reports of their feelings at the time of diagnosis and staging, as well as their perceptions of how diagnosis and staging affected their parenting. Furthermore, the study included personal accounts of various coping strategies used by maternal breast cancer survivors to manage the psychological effects of their diagnosis.

My methodology included a sampling selection strategy involving participant criteria, instrument development, and a pre-study test of the instrument. Following a discussion about instrumentation, I will present procedures for recruitment, data collection, and analysis. Chapter

3 ends with a discussion of trustworthiness, ethical procedures, and the role of the researcher, as well as a summary and a conclusion.

Research Design and Rationale

According to Creswell (2012), a qualitative research paradigm involves the following rationales: (a) research questions begin with *how* and *what*, (b) the topic requires examination because of multiple variables and/or a lack of theory, and (c) data are gathered in participants' natural settings. I chose this paradigm because expressed language (i.e., verbal communication) is more indicative of the experience of understanding and learning within contextual conditions. Through the use of a qualitative approach, I recognized the importance of the subjective creation of meaning and enabled research participants to tell their stories.

Given the nature of the inquiry and research questions in this qualitative study, a case study design was the best fit. This approach was ideally suited to exploring issues in depth and following leads into new areas to develop new theories. Indeed, the theoretical framework that exists at the beginning of a study may not be the same one that survives to the end (Hartley, 2004). According to Yin (2004), theory development facilitates not only the data collection phase of the ensuing case study but also the theory building phase.

Research Questions

I developed two primary research questions, each with three sub-questions, to guide this study. The questions were as follows:

Research Question 1: What coping mechanisms did women use to manage their breast cancer diagnosis, staging of cancer, treatment, and aftermath of their cancer experience?

Sub-question 1: Did the diagnosis of breast cancer and staging affect the manner in which a woman copes with psychological stress?

Sub-question 2: Did breast cancer treatment affect a woman's psychosocial functioning and how she interacted with her children and others?

Sub-question 3: Did the experience of breast cancer have an impact on a woman's capacity to manage the uncertainties of survivorship, specifically fears of recurrence?

Research Question 2: Did communication between mothers and their children change on account of their breast cancer diagnosis?

Sub-question 1: Did communication between mothers and their children change prior to the breast cancer diagnosis?

Sub-question 2: Did communication between mothers and their children change during cancer treatment?

Sub-question 3: Did communication between breast cancer survivors and their children change post-treatment?

Research Tradition and Justification

Researchers have used qualitative methods to provide complex descriptions of how people experience a given research issue (Creswell, 2013). Qualitative methods provide an effective way to identify intangible factors, such as social norms, socioeconomic status, gender roles, ethnicity, and religion, whose role in the research issue may not be clear. Researchers can also use qualitative methods to probe further into participant's initial responses, asking why or how in order to gather more detailed data.

According to scholars (Creswell, 2013; Yin, 2014), qualitative research cannot be justified under positivist assumptions, and it is therefore linked to a subjective, phenomenological epistemological position. Under an empiricist and/or subjective theory of being, the views of actors, as communicated through case studies, are empirical points of

departure. Investigators use qualitative research methods to understand people in their social and cultural contexts.

Kaplan and Maxwell (1994) argued that the goal of understanding a phenomenon from the point of view of the participants and their social and institutional contexts is largely lost when researchers quantify textual data. It follows that the choice of a specific qualitative research method is independent of any underlying philosophical position. Thus, case study research can be positivist (Yin, 2004), interpretive (Stake, 2000), or critical, just as action research can be positivist (Creswell, 2013).

Creswell (2012) argued that the qualitative approach allows researchers to obtain a better understanding of the human experience. Given that I was interested in the lived experiences of mothers who are breast cancer survivors, the qualitative paradigm constituted the best approach for this study.

Multiple Case Study Design

Some researchers have used case studies to (a) examine the relationship between early breast cancer staging and its effects on communication patterns between mothers and their children, (b) explore how mothers manage communication with their children when facing health uncertainty, and (c) investigate coping mechanisms of early-stage maternal breast cancer survivors. Several scholars (Al-Zaben et al., 2014; Batenburg & Das, 2014; Campbell-Enns & Woodgate, 2013; Donovan-Kicken et al., 2012; Molina et al., 2014) have conducted studies primarily focused on how parental cancer affects the psychosocial needs of cancer patients in relationship to the psychosocial needs of their spouses, children, family, and friends.

Some inquiries (Al-Zaben et al., 2014; Forrest, Plumb, Ziebland, & Stein, 2009) have included the effects of late-stage breast cancer (Stages IIIA/B and Stage IV) on developing end-

of-life communication protocols between patients, their spouses, and their children. I selected the inductive case study design for this study over other designs because my research questions were focused on capturing in-depth information about the lived experiences of maternal cancer survivors, rather than specific frequencies or answers. Specifically, I aimed to construct a broader picture of the perceptions and experiences of maternal cancer survivors with a diagnosis of early-stage breast cancer (Stage 0, Stage IA, IB, IIA, and IIB).

The interview format resulted in rich descriptions and accounts from maternal cancer survivors about their understanding and perceptions of motherhood before initial diagnosis, during treatment, and during staging. My use of the case study approach allowed mothers an opportunity to be descriptive about their understanding and experiences of how cancer staging affects the mother-child bond and patterns of communication (see Gazendam-Donofrio et al., 2009). I used in-depth, semi-structured questions to gain a better understanding of how maternal cancer survivors constructed interpersonal meaning from the trauma and uncertainty of cancer.

A multiple case study was necessary to gather data about how maternal cancer survivors communicated throughout their cancer experience, especially within the mother-child relationship. To understand this dynamic connection, the multiple case study interviews allowed for the construction of narrative accounts of the human experiences (e.g., struggle, fear, hope, coping, and survival) of mothers with cancer. The multiple case study design allowed me to compare and contrast participants' experiences. Furthermore, interviews provided opportunities to examine specific issues introduced by respondents themselves.

Conceptual Framework

For the primary conceptual framework of this study, I included Lazarus and Folkman's (1984) theory of psychological coping and McMaster's family systems theory of communication

(Epstein et al., 1993). Additionally, I included generalist notions of psychosocial functioning and Carstensen's theory of socioemotional selectivity (Carstensen, 1992) as secondary, consequential theories. Psychosocial functioning is an underlying factor in coping. Moreover, socioemotional selectivity may be included in perceptions of a shortened lifespan (Sullivan-Singh et al, 2015).

Scholars define coping as a conscious psychological response to an individual's experience of stress. Coping is how an individual manages stress imposed by environmental factors and intrapsychic phenomena (Lazarus & Folkman, 1984). Two factors contribute to an individual's stress: (a) perceptions of threat and (b) assessment of resources available to tolerate, limit, or eliminate stressors and the stress they produce (Lazarus, 1993). Furthermore, individuals use cognitive appraisal to construct an understanding of their stressful experience. Narratives of primary appraisal include thoughts like, "This is stressful" or "This is too much to handle." Secondary appraisal may include narratives like, "I can deal with this" or "If this does not work, there is another way."

I examined the effects breast cancer diagnosis, stage of breast cancer, and breast cancer treatment on mothers' coping mechanisms and communication patterns between mothers and their children to guide the methodology (see Figure 1). The anticipated outcome of this process was to obtain rich data from a line of inquiry that examined (a) coping categories and mechanisms that mothers use to manage stress due to breast cancer diagnosis and health uncertainty, (b) use of cognitive appraisal (primary and secondary) in coping and managing stress, (c) maternal fears, concerns, and hopes within the context of breast cancer survivorship, (d) communication patterns between mothers and their children before diagnosis and staging, throughout treatment, and post-treatment, and (e) themes of effective (open or problem-focused) and ineffective (emotional or avoidant) communication strategies.

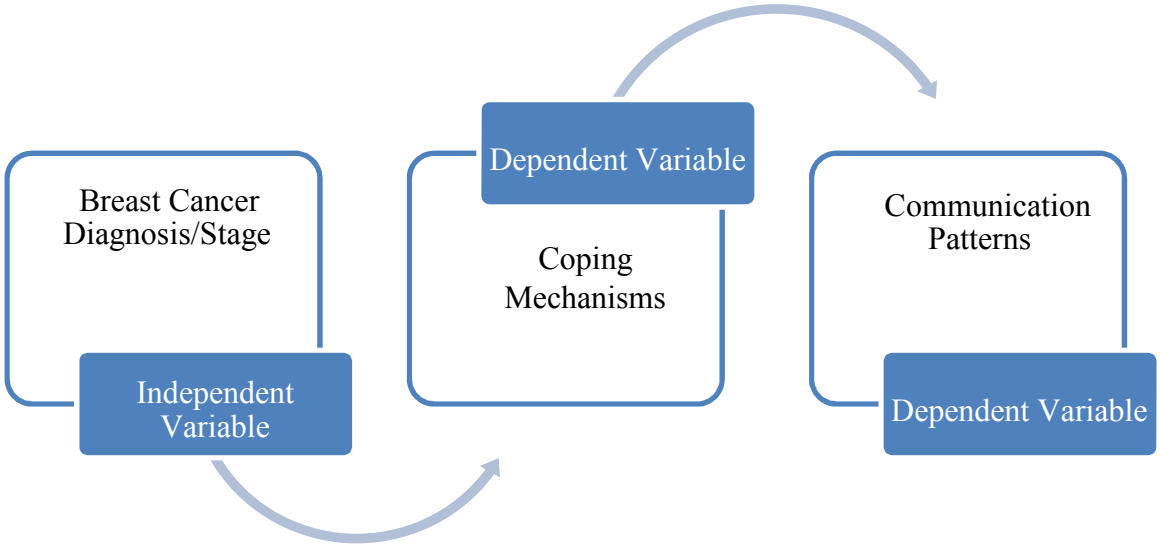

Figure 1. Conceptualization of the relationship of adaption to cancer diagnosis/ staging, coping, and communication.

Methodology

Using engagement through each case with comparisons to the collective cases, the purpose of this study was to investigate how maternal breast cancer survivors constructed meaning from their shared experiences of being a woman, a mother, and a breast cancer survivor; I also aimed to examine at how they as individuals, as groups, and as sub-groups made sense of their parental role(s) at the time of their diagnosis, during treatment and recovery, and after remission, as well as their concerns about recurrence of the cancer. I was specifically interested in data between cases, particularly with regard to staging, the mother-children bond, communication patterns with children, and coping.

The goal was to contrast findings across cases and draw comparisons between cases in two groups of early-stage breast cancer (Group 1: Stage 0-IA/B breast cancer and Group 2: Stage IIA/B breast cancer). I chose these groups so that I might compare experiences based on

diagnosis/staging and the coping mechanisms that women use to deal with health adversities and uncertainty. In addition, I hoped to determine how breast cancer diagnosis and staging might be a factor in mothers' bonds with their children and their management of communication strategies. Moreover, by using a qualitative, multiple case study approach with two groups, I identified comparable results across cases based on one or both of the theoretical constructs (coping strategies and types of communication).

In my qualitative, multiple case study, I included a purposive sample of 20 maternal breast cancer survivors from a university-affiliated outpatient breast cancer center on Long Island, New York. The center is the largest community-based program in the area for breast cancer survivors. Its primary locale provides outpatient medical services, psychosocial support, and research for hundreds of breast cancer survivors and their families. Four staff members from the center and/or team (a physician, social worker, nurse practitioner, and a patient- community advocate) assisted me in accessing the sample population. In addition to my dissertation committee, the site research team assisted me in the recruiting processes and provided feedback about the interviewing process and interview questions during the pre-test phase of the study.

The purpose of the pre-test phase was to elicit feedback from members of the dissertation committee and research team about activities and techniques for interviews. Pre-testing ensured that interview questions were (a) matched with research questions and grouped according to the appropriate theme or topic, (b) clear and understandable, (c) believable and realistic, (d) culturally appropriate, (e) sensitive to research participants, (f) meaningful, (g) motivational, and (h) informative. Furthermore, pre-testing provided an opportunity to discuss and trouble-shoot both expected and unforeseen issues.

Participant Criteria

To meet the criteria for sample selection, participants must (a) be female breast cancer survivors, (b) have a diagnosis of early-stage breast cancer (Stage 0 – Stage IIB), (c) be post-treatment for at least one year, and (d) have at least one child ranging in age from 3 to 16 years of age at the time of initial diagnosis. I divided participants into two categories of breast cancer stage and used the stage at the time of diagnosis to obtain a clearer understanding of differences and similarities among and between participants. Each group had 10 participants who fit the criteria for their respective groups. As criteria for inclusion, the focus was on common traits and differences within each category; this focus was the same between the two groups.

In accordance with the proposed research questions, the lack of research about the research topic, and accessibility to the sample, I used a purposive sampling of 20 maternal breast cancer survivors. I placed participants in one of two categories: (a) 10 maternal breast cancer survivors who progressed from Stage 0 breast cancer to Stage IA/B breast cancer and (b) 10 maternal breast cancer survivors initially diagnosed with Stage IB breast cancer who progressed to Stage IIA/B breast cancer. Those cancer patients who did not meet these criteria were not eligible for participation in the study.

Sample Selection

I used a purposive sampling strategy commonly useful in qualitative research studies (Yin, 2014). By utilizing a purposive sampling, I reinforced a sample selection strategy relevant to criteria that fit the research questions. Moreover, a purposive sampling strategy clarified the aims of the research and maintained the central importance of the study. Factors that affected sample size included available resources, time for the study, and researcher's objectives.

The sample selection for this study included 20 women from the North Shore and South Shore communities of Long Island, New York. The average age of the women was 35 years old. The sample selection represented various ethnic and socio-economic backgrounds. Level of education also varied, from high school diploma/GED and BA/BS degrees to Masters-level and post-Masters degrees. Sixteen out of the 20 women worked full time (an average of 37.50 hours a week). Three of the women worked part time (an average of 21 hours a week). One of the women was unemployed (out on disability), but volunteered at a nursing facility.

Instrument Development

The Interview Guide

Before conducting interviews, I designed an interview guide for data collection. In developing the interview guide, I considered three important factors: (a) the focus of the inquiry and/or the research question(s), (b) information reported by participants, and (c) time and type of access available to conduct interviews. With this as the context, I developed an interview guide consisting of five sections related to the research questions. The interview guide included semi-structured questions (see Appendix D for details).

Part 1 of the questionnaire included demographic and background information: (a) date of the interview, (b) chosen pseudonym for the participant, (c) mother's age, (d) number of children, (e) age of each child, (f) marital status, and (g) group identification (group 1 or group 2). Part 2 included three questions about the emotional impact that breast cancer and staging had on the participant at the time of initial diagnosis, including the emotional effect of staging on her parental role. Part 3 encompassed the psychosocial experience of the initial diagnosis and the participant's perceptions of how breast cancer and staging affected her life as a woman, a

mother, and a wife; it also examined the patient's perception of how breast cancer and staging affected her family.

Part 4 relates to RQ1: What coping mechanisms did women use to manage their breast cancer diagnosis, stage of cancer, treatment, and aftermath of their cancer experience? Participants had an opportunity to answer three sub-questions about descriptive definitions within the context of maternal breast cancer survivorship (e.g., Lazarus and Folkman's theory on coping: primary and secondary cognitive appraisal, problem-focused vs. emotional focused). The sub-questions focused on (a) maternal understanding of what coping and coping mechanisms means to them, (b) what helped mothers cope during their breast cancer experience, (c) maternal reports (if they answered the second question in Part 5) regarding how mothers used chosen methods of coping to manage their breast cancer, and (d) effects of breast cancer on becoming stronger women and parents.

Part 5 had a focus on RQ2: Has communication between mothers and their children on account of their breast cancer diagnosis changed? Participants had an opportunity to answer three sub-questions about descriptive definitions within the context of maternal breast cancer survivorship (e.g., McMaster's family communication theory: open and direct vs. avoidant and indirect, problem-focused vs. emotional- focused). The sub-questions focused on (a) how mothers define communication, (b) the types of communication that mothers used at different stages of breast cancer, (c) how communication changed over time during the different stages of the cancer continuum (before diagnosis and staging, at the time of diagnosis and staging, during treatment, and post-treatment), and (d) communication changes between mothers and their children during the different stages of the cancer continuum.

Part 5 ended with two concluding questions. The first asked if the participant would like to add anything further. The second asked if the participant would like to provide advice to other women with early-stage breast cancer in terms of communicating with family members about coping with the disease. Additional time was available for the investigator to gain participant feedback and to review narrative content for additional clarity.

Review of Interview Guide

Prior to the first interview, I reviewed the interview guide and pre-tested interview questions with the medical team. The pre-test ensured that the interview questions focused on the research questions and that the interview questions were clear and applicable to participants' lives. This pre-test phase ensured that participants understood the questions in the correct order. The constructive feedback from the research team was useful in identifying whether additional or more specific questions were required and whether other questions should be disregarded.

With the team's permission, I audio-taped the pre-testing session and took field notes to document ideas. I then used data from the group to refine the interview questions. The interview questions provided a method with which to describe the meanings of central themes seen among mothers who were breast cancer survivors. The thematic structure of the questions included (a) breast cancer survivorship within the context of motherhood, (b) breast cancer staging, (c) communication patterns between mothers and children, (d) changes in perceptions and use of time since diagnosis and staging, and (e) mothers' psychosocial coping skills through communication strategies.

At the end of each interview, I provided additional time to review content with participants and to achieve narrative accuracy. I used feedback from participant responses as a check on the validity of my interpretation(s). This additional time allowed me to affirm that my

summaries reflected participants' views, feelings, and experiences. A discussion with participants about their responses allowed them the opportunity to critically analyze my findings and provide clarity for my interpretations. Importantly, the additional time also improved the applicability of the study and therefore provided findings that were reliable, original, and authentic.

Research Procedures

Recruitment

1. After receiving approval from the cancer center (refer to Appendix A for research site invitation and approval) and Walden University (Walden IRB approval number 06-22-16-0037060), I met with the research team to review the study objectives. The medical team included an attending oncologist, oncology social worker, oncology nurse practitioner, and the center's patient and community advocate (PCA). At this meeting, we reviewed and discussed the purpose of the study and the criteria for participant selection, while reinforcing ethical and systematic procedures for recruiting participants. Each team member received an information flyer solely for recruitment purposes. The flyer included the purpose, criteria, dates, times and location for the interviews, notice of audio-recording, and follow-up interviews (refer to Appendix B for flyer details).
2. I was the primary contact for the team and participants. The team served as coordinators for guiding prospective participants to the flyers and my contact information.
3. Confirmation of logistical concerns such as meeting space for the interviews, audio equipment, and other provisions took place.

4. The PCA hung the flyer in enclosed bulletin boards throughout the cancer center. Copies of the flyer were available in the offices of the PCA, social worker, nurse practitioner, and attending physician.
5. Prospective participants contacted me and completed an interest to participate in research form, or IPSF (see Appendix C for IPSF form). I also answered initial questions, scheduled interviews, and gave prospective participants my professional phone number for questions and concerns.
6. I collected all demographic information, including the IPSF, and confirmed the days and times of interviews with participants.

Interview Procedures

I met with participants in a quiet, comfortably spacious private office within the cancer center. Although the cancer center provided bottled water and snacks at no charge for study participants, participants also had access to a number of vending machines for beverages and snacks, as well as convenient rest rooms. Cancer center volunteers were available to watch children in the playroom if needed during the interview. In the event of an emergency, volunteers were prepared to notify an available member of the research team, who would then inform myself and the participant.

Using a script, I built rapport by welcoming the participant, introducing myself, and briefly sharing my background. I reviewed confidentiality practices, rights, and privileges and confirmed completion and signing of the consent form (refer to Appendix E for consent form). As part of the process, I asked the participant if I might record the interview, the purpose of which was to record participant responses. I confirmed the participant's basic demographic information - name, address, phone number- and other information on the IPSF.

Next came an explanation of the interview's purpose, the study's importance, critical aspects of the research, the format of the interview, and indications of how long the interview might take. I informed participants that they did not have to answer questions that evoked discomfort and that they had the right to end the interview at any time. I told participants that counseling was available to them should they require emotional support during and/or after the interview. Prior to beginning the interview, I asked participants to choose a pseudonym for the study. Additionally, I asked participants if they had any questions and/or concerns and told them how to get in touch with me if questions or concerns arose after the interview. Furthermore, I provided details regarding the structure of the interview process.

During the interview, I asked one question at a time and confirmed participants' understanding of the question. I attempted to remain as neutral as possible by not showing strong emotional reactions to their responses; while I encouraged responses with occasional nodding, I refrained from other non-verbal cues and/or body language. I provided a transition between major topics (e.g., "We've been talking about coping, and now I'd like to move on to. . ."). I maintained control of the interview process, bringing participants' attention back to the question at hand when they strayed to another topic, took long to answer , or even began asking me questions themselves.

I engaged participants by using basic counseling skills to reinforce validation and appreciation of their participation. Maintaining focus, listening intently, and keeping the interviews moving at an appropriate pace prevented undue time from elapsing. Interviews ran between one and a half to two hours. Participants had restroom and refreshment breaks during the interview to help ease physical and emotional needs. At the end of the interview, I thanked each participant for her participation. I scheduled a follow-up phone conference to provide the

opportunity for the participant and myself to clarify answers, ask questions, or address concerns regarding the interview process.

Data Collection

Interview recording is the most common method of collecting qualitative data; the primary advantage of recording was that it gave me the ability to preserve the entire verbal part of the study. I recorded the personal views and meaningful descriptions of lived experiences from my chosen sample using a laptop equipped with a built-in microphone. I used the recorded responses from each participant to capture verbal content initiated specifically from the interview questions. A fully charged laptop battery ensured proper and continued recording in the event of unforeseen power outages. In the event of a laptop malfunction, I was prepared to use an alternate recording device (i.e., TASCAM DR-05).

Importantly, I used recall as part of the process to identify significant participant non-verbal reactions like bodily expressions and gestures, as well as related interactions between myself and participant. Given the highly emotional nature of the population sample, some participants responded non-verbally (e.g. tearing of eyes, sighs, covering of face with hands, tightening of fists, finger tapping, arm rubbing, leg bouncing, fidgeting, etc.). Recalling events was a challenging way of collecting data, but had advantages in relation to the goal of collecting "non-verbal" information from respondents. After each interview, I checked the recordings for errors and prepared the tapes for transfer to transcription software (NVivo).

Data Analysis Plan

The data gathered from women's personal observations during face-to-face interviews were the focus of the analysis. I transcribed the contents of each interview into statements to develop a concept map of the women's accounts of coping strategies and methods, as well as

communication styles and communication patterns with their children before breast cancer diagnosis, at the time of diagnosis, during treatment, and post-final treatment.

Within the concept cloud for coping, six components emerged: (a) coping strategies and methods used before diagnosis, (b) initial reactions to breast cancer diagnosis, (c) initial reactions to breast cancer stage, (d) coping strategies and methods used at the time of diagnosis, (e) coping strategies and methods used throughout treatment, and (f) coping strategies and methods used after the last cancer treatment. I constructed an additional concept map to form a composite map, showing differences and similarities within and between groups (Stage 0/I and Stage II).

Using a similar approach to the data for coping, I conceptualized communication as a continuum of communication during the five time periods: (a) before diagnosis, (b) at the time of diagnosis, (c), at the time of staging, (d) throughout treatment, and (d) after the last cancer treatment. Within the concept cloud for communication patterns, five components emerged: (a) communication styles and patterns before diagnosis, (b) communication styles and patterns at the time of diagnosis, (c) communication styles and patterns at the time of staging, (d) communication styles and patterns throughout treatment, and (e) communication styles and patterns after the last cancer treatment. I constructed an additional concept map to form a composite map, showing differences and similarities within and between groups (Stage 0/I and Stage II).

In this case study, each case represented a thematic finding, such as the similarities and differences in (a) coping mechanisms used by mothers before breast cancer diagnosis/staging, at time of diagnosis, and staging, throughout treatment, and post-treatment and (b) communication patterns between mothers and children before and throughout the cancer continuum into

survivorship. I analyzed and discussed each of the cases in terms of a small number of pervasive and important themes. Establishing the significance or importance of themes or findings was crucial because the discussion should ideally link these themes to larger theoretical and practical issues (Creswell, 2014). Using the two groups (Stage 0-IA/B and Stage IA/IIB), I compared and contrasted each experience by noting similarities, differences, and factors not otherwise considered. This data derived from in-depth interviews, involving face-to-face discussions with human subjects and a "best fit" approach for capturing meaningful data.

Step 1. After the conclusion of each the interview, I entered the data from the semi-structured interviews and field notes into laptop files.

Step 2. I added the chosen pseudonyms and demographic data to NVivo's creating cases feature. Participant data were organized according to group.

Step 3. I imported audio data from the laptop file to transcription software. Interview transcription was a continuum from an audio file and incorporated every sound recorded (breaks, sighs, stammers, etc.) to a transcript restricted to sentences of relevance to the specific research questions and interview questions.

Step 4. Before coding the data, I used the NVivo node feature to gather and organize referenced data from text content. The nodes helped to identify interview responses associated with coping and communication within groups and between groups.

Step 5. I identified similarities and differences in the data using *coding* and *labeling.* Since the study was qualitative, a system for pre-coding did not exist; rather, *content analysis* was useful as a method of identifying, labeling, and coding. I summarized content by counting various aspects of participant responses.

The purpose of coding was to make sense of the data and to highlight findings. I used this method to categorize verbal or behavioral data for the purposes of classification, summarization, and tabulation. Once I gathered data under descriptive codes, thematic patterns emerged: (a) initial reactions to breast cancer diagnosis and stage, (b) categories of coping, and (c) the effects of breast cancer diagnosis/staging on coping and communication patterns between cancer survivors and their children.

I used the model explorer option in NVivo to illustrate relationships between themes. NVivo lends itself this type of analysis on two levels: (a) the basic level, a descriptive account of the data of expressed/verbal language, but without theories or comments as to why or how and (b) the higher or latent level of analysis, more interpretive and concerned with the responses, as well as with their inferred or implied meaning.

Issues of Trustworthiness

The idea of *trustworthiness* replaces the idea of discovering truth through measures of reliability and validity (Mishler, 2000), which according to Johnson (1997) was defensible in establishing confidence in the findings (Lincoln & Guba, 1985). If the issues of reliability, validity, trustworthiness, quality, and rigor were differentiating "good" from "bad" research, then testing and increasing the reliability, validity, trustworthiness, quality, and rigor would be important for research in any paradigm.

Unlike quantitative studies with statistical methods for establishing validity and reliability of research findings, the purpose of qualitative studies was to design and incorporate methodological strategies to ensure the trustworthiness of the findings. Lincoln and Guba (1985) identified four strategies: (a) *truth value*, which is a researcher's confidence in the study topic, purpose, importance, design, sample selection, and truth of the findings based on the lived

experiences of participants, (b) *applicability*, which is the degree to which the researcher's findings can be applied to other contexts or with other groups of people, (c) *consistency*, which is the degree to which the researcher's findings would be similar to inquiries with the same context or topic, and (d) *neutrality,* which is the degree to which findings are based solely on the participants' experiences and the conditions of the research.

To ensure trustworthiness, I planned and implemented strategies by (a) engaging with my research team and dissertation committee members to reduce researcher bias, (b) limiting bias in sampling, data collection, and data analysis, (c) maintaining audio and written records to demonstrate consistent and transparent interpretations of data, (d) constructing a method to compare and contrast cases to demonstrate the representation of similar/different perspectives, (e) including verbatim descriptions of participants' accounts based on primary and secondary research questions, and (f) conducting a review of the interview with participants to clarify or validate responses, concepts, and themes.

Credibility

Establishing the credibility of the study involved showing compatibility between the constructed realities that exist in the minds of the participants and their attributions. Collecting these narratives through case studies involved the use of probing interview questions based on the research questions. To establish the credibility of the study, I used *peer debriefing*, *persistent observations*, *prolonged engagement, member checks (follow-up exposure),* and *referential/interpretive adequacy.*

Peer debriefing with the research team and my dissertation committee provided an in-depth review and critical analysis of content. The research team and dissertation committee offered feedback and insights to further credibility. Re-examining the sources of data via

member checks provided a way to (a) assess intentionality of respondents, (b) correct errors, (c) provide additional participant information, (d) summarize the first step in data analysis, and (e) assess the overall adequacy of the data, in addition to individual data points.

Persistent observations help researchers identify patterns and characteristics that emerge from the inquiry and that are most relevant to the problem (Lincoln & Guba, 1985). I used persistent observations and prolonged engagement as a way to go beyond observation to gain a richer, deeper understanding of mothers' behaviors and relationships in a social context (i.e., with their children and family members). At the end of each interview, participants' responses underwent a process of assessment and confirmation to ensure the correctness of my behavioral and conversational interpretations.

Referential or interpreted adequacy ensured an accurate portrayal of the data. I solicited participant feedback about the accuracy of their responses through member checks or follow-up, which included detailed descriptions and precise quotations. The goal of the use of verbatim quotations was to give the participant an opportunity to *hear* her responses. By reviewing the content of the interview, a participant could either validate or augment the researcher's perception, understanding, and interpretation of her feedback.

Transferability

According to several researchers (Creswell, 2013; Francis et al., 2010; Stake, 2005; Yin, 2014), the obligation to demonstrate transferability and/or extent to which the findings can be applicable in other contexts or with other respondents belongs to the reader of the study. In this study, strategies for transferability include two major components:

1. A complete, in-depth description of what occurred in the interviews. It was my responsibility to include sufficient data that provided detailed descriptions of data in

context. Findings must be reported with precision to allow judgments about transferability to be made by the reader (Yin, 2014).

2. In contrast to random sampling, I used purposive sampling to provide a representative picture of the characteristics and qualities applicable to a particular sub-set of people. My use of a purposive sampling strategy secured specific profile characteristics. Moreover, the use of purposive sampling can maximize the range of specific information obtainable from, and about, the context (Yin, 2014).

Dependability

The dependability of a qualitative study involves a system of checks and balances with regard to conceptualizing the study, collecting the data, interpreting the findings, and reporting results (Creswell, 2012). Included is the logic for the selection of people and events to observe, the interview protocol, and the clarity of the study. More consistency derives from the investigator being part of the research process, producing a more dependable result.

For this study, a *dependability audit* allowed for an independent auditor to review my activities (as recorded in an audit trail in field notes, archives, and reports). Independent auditor reviews included feedback from my dissertation Chair and other committee members, who assessed how I used techniques for meeting the credibility and transferability standards. To avoid the diminishing of dependability and trustworthiness, I maintained an audit trail.

According to the seminal work by Lincoln and Guba (1985), close ties between dependability and credibility exist. However, in order to address dependability concerns, the processes of this study should enable another researcher to replicate the work. In-depth reporting included a thorough understanding of the methods and the effectiveness of those methods. I included a description of the research design and implementation of the design, as well as what I

planned and executed on a strategic level to answer the research questions. Furthermore, I also included the operational details of data collection and a reflective appraisal of the research process.

Confirmability

Confirmability is the degree to which the findings of the study are the product of the focus of the inquiry and not of the biases of the researcher. Furthermore, confirmability is the degree to which the researcher confirms or corroborates findings by others. The term is analogous to objectivity, the extent to which a researcher is aware of, or accounts for, individual subjectivity or bias (Kaplan & Maxwell, 1994).

A confirmability audit trail involved a methodological, self-critical account of how I conducted the study. In order to make auditing possible by other researchers, all collected data was kept in a well-organized, retrievable form, so that findings were available for possible challenges from participants and from others who review the study. I left an adequate auditing trail to enable readers to determine whether the conclusions, interpretations, and recommendations were traceable to their sources and supported by the inquiry.

In their seminal work, Lincoln and Guba (1985) noted that Halpern (1983) suggested six classes of raw record data for review: (a) raw data (interviews, recorded audiotapes, field notes, etc.), (b) data reduction and analysis products (write-ups of field notes, summaries and condensed notes, theoretical notes, concepts, and hunches), (c) data reconstruction and synthesis products (themes developed, findings, conclusions, and final report), (d) process notes (methodological notes, trustworthiness notes, and audit trail notes), (e) material relating to intentions and dispositions (research proposal, personal notes, and expectations), and (f) instrument development information (pilot testing of interview questions, forms, and schedules).

Yin (2014) described a range of case study strategies available through the use of a protocol. This overview of the whole research process encompasses an identified instrument of analysis, the researcher's procedures, and the format of the case study report. The case study protocol is an important guide for keeping a case study focused. I used a case study protocol when multiple case studies required external validation to demonstrate a clear research pathway. Specifically, this pathway involved (a) an overview of the case study project, (b) field procedures, including ethical considerations, (c) case study questions and analysis instruments, and (d) a plan for how I expected to write the case study report.

Ethical Procedures

In order to ensure the ethical protection of research participants, I did not contact any research participant or collect any data until I obtained approval from both the cancer center (see Appendix A) and Walden University IRB (IRB approval number 06-22-16-0037060).

Once approved by both sources, I reviewed with participants the purpose of the study and its requirements, as well as a statement of confidentiality. Before the interviewing process, I encouraged participants' questions and reaffirmed that they would not experience any harm. In the event that a participant became emotionally distraught, a clinical social worker was available for intervention. This research study included voluntary in-person and telephone interviews if and/or when necessary.

Although the interview questions were not highly sensitive in nature, I reinforced anonymity and confidentiality by not using the names of research participants. Informed consent forms ("Rights and Privileges"), which included a brief statement indicating their willingness to participate, was an expression of participants' consent. Each participant reviewed and considered their participation prior to the interviewing process. Each had the right to privacy and to opt out

of participation at any time. If a participant was unable to come for her interview due unforeseen circumstances, I offered an alternative date and time. If a participant chose to drop out of the interview process altogether, I replaced her with an individual from a waiting list.

I did not attribute specific comments or responses to any one individual or in a manner from which others might assign data to a specific individual. Should they desire, participants had access to the findings of the study. I was ethically bound to the institution that sanctioned the study to provide the results of the study. Once I analyzed the data, I reported my findings to the dissertation Chair and other committee members. When they approved the study, I scheduled a meeting with the participants and the medical team to discuss those same findings.

Role of the Researcher

According to Yin (2004), a researcher's responsibility is to convert a complex phenomenon into a format readily understood by the reader. The goal is to describe the study in a systematic, comprehensive manner, enabling the reader to feel as if they had been an active participant in the research and to determine whether the findings of the study apply to their own situation. Importantly, I described the context within which the study phenomenon occurred, as well as the phenomenon itself. Stake (2000) argued that no one correct way exists to report a case study. Some scholars (Creswell, 2013; Willig, 2008) have suggested ways to provide a chronological report or address each proposition. According to Creswell (2013), the researcher is an instrument of investigation and must aspire to constant reflection, recognizing and acknowledging the unavoidable biases that are inherent in the research process.

As the researcher for this study, I am a male residing and working as a clinical social worker on Long Island. My interest in the study topic is personal, professional, and academic. My mother succumbed to metastatic breast cancer when I was 16 years old. I can recall the

effects of maternal cancer and cancer staging on our family's interpersonal dynamics and communication patterns. From personal experience, I observed my mother's "urgency" to utilize and maintain her maternal identity for coping with breast cancer, while building psychological resilience to help manage anxiety that often accompanied uncertainty.

Because of my personal experience, I developed a profound interest in social work oncology and have extensive experience providing oncology social work services to pediatric, adolescent, and adult cancer survivors in hospital and outpatient settings. The inspiration for the study was the experience of my youngest sibling's diagnosis of Stage II breast cancer. From my first-hand observations, I noted how my sister's diagnosis and staging affected her bond with her daughter.

The desire to transform my anxiety, fear, and helplessness rekindled a desire, focus, and commitment to affect positive change in the lives of cancer survivors, particularly among mothers with cancer. During my sister's years of outpatient treatment, I had numerous opportunities to speak with maternal cancer survivors from Long Island. Those meaningful interactions, and these women's lived experiences, became the primary force behind my desire to tell their stories about being women, mothers, and cancer survivors.

Summary

The rationale for this study was my personal and scholarly interest in the relationship between maternal breast cancer and the effects of mother-child bonding on maternal coping and resilience. My reflections on other variables within this relationship, such as diagnosis and staging as factors affecting communications patterns between a mother and her child, helped initiate the development of a scholarly study based on (a) McMaster's theory of family systems communication and (b) Lazarus and Folkman's transactional model of stress and coping, both

discussed in Chapters 1 and 2. Given the nature of the research questions and the desire to understand participants' motivations and perceptions, a qualitative methodology was appropriate to collect data and to better understand the lived experiences of mothers diagnosed with early-stage breast cancer.

A multiple case study design using interviewing protocols, tools, and questions was the means of collecting meaningful data from 20 maternal breast cancer survivors (Stage 0-II breast cancer). Once I obtained approval from the Dissertation Committee IRB at Walden University and the cancer center, procedures for participant recruitment and pre-testing of interview questions were conducted with designated cancer center staff (the center's patient and community advocate, attending oncologist, social worker, and nurse practitioner). I used qualitative data analysis software packages to organize and analyze data. Furthermore, I used the QDA to identify and uncover patterning of words, phrases, meaningful themes, and shared experiences among and between maternal breast cancer survivors, based on interview questions.

Conclusion

Chapter 3 provided a description of the methodology used to design the rationale for the researcher's choices. I included a description of the population and participants, my role, the data collection tools, and data collection plan. I also included a plan for data analysis and discussion about issues of trustworthiness. I maintained an open, reflective point of view during the research process, which included (a) writing the research proposal, (b) networking with professions at the cancer care site, (c) creating interview questions, (d) selecting participants for the sample, (e) organizing the schedule for interviews, and (f) collecting and analyzing data. Once I analyzed the data, I reported on the findings in Chapter 4.

Chapter 4: Findings

Introduction

In this chapter, I describe the data collected from 20 in-depth interviews conducted to understand the interrelationship among several variables, including cancer staging, communication, and psychosocial coping among maternal breast cancer survivors. The units of analyses were the effects of early-stage breast cancer diagnosis, cancer stage, and treatment on coping mechanisms and communication patterns between mothers and their children. I completed 16 interviews at the Carol M. Baldwin Breast Center and four at participants' homes.

This chapter includes (a) an introduction, (b) a presentation of participant demographics, (c) a presentation of the findings, (d) a summary of the findings, and (e) a conclusion. Data analysis includes my report and description of categories, as well as themes that emerged from each interview. Throughout this chapter, I have identified participants by their group (G) and number (1 or 2) after their names. Each section contains a summarized analysis of the findings from G1 (breast cancer stage 0, IA, IB) and G2 (breast cancer stage IIA, IIB).

Part 1 includes G1-G2 categories and strategies of coping used by breast cancer survivors before diagnosis, at time of diagnosis, at time of staging, throughout treatment, and post-treatment into survivorship. Part 1 also includes patients' initial emotional reactions to cancer diagnosis and cancer staging. Part 2 includes primary and secondary styles of communication patterns between mothers and their children before diagnosis, at time of diagnosis, at time of staging, throughout treatment, and post-treatment into survivorship. Part 3 includes descriptions of the coping mechanisms used by mothers before diagnosis, at time of diagnosis, at time of staging, throughout treatment, and post-treatment into survivorship. Part 3 also includes descriptions of communication patterns between mothers and their children before diagnosis, at

time of diagnosis, at time of staging, throughout treatment, and post-treatment into survivorship. Part 4 includes a discussion of advice from participants to current and future breast cancer survivors. Chapter 4 concludes with a summary of answers to each of the research questions and a closing summary with a transitional statement to Chapter 5.

Demographics

Demographic data included the chosen pseudonym of each participant and family composition broken down by (a) the number of children at the time of diagnosis and treatment, (b) the ages of each child at the time of diagnosis and treatment, (e) the gender of each child, and (f) participant's marital status. Participants chose a pseudonym to protect their identities and selected these pseudonyms according to personal preference and meaning. I found that the number of children affected how women managed communication and stress; women who parented more than one child reported greater psychosocial stress than women with one child.

Children's ages also influenced women's choices of communication type and coping strategy. Women used their child's age and developmental stage to determine how they would interact with each child. The child's gender also affected participants' interactions with their children, as women related to their children within the context of a mother-daughter or mother-son relationship. Women who were married and/or partnered relied on these relationships for emotional support from the time of diagnosis throughout the duration of treatment. Single, widowed, and divorced participants did not have similar, intact relationships to support them.

G1 Demographics: Family Composition and Marital Status

As shown in Table 2, the family composition of G1 participants included 1-4 children, with 12 females and 9 males. One participant recalled having difficulty parenting four children throughout her breast cancer experience (i.e., managing personality differences and

developmental needs). The ages of children at the time of diagnosis and treatment ranged from 3 to 12 years of age. Four participants reported that their 7- and 8-year-old sons exhibited behavioral problems at home and in school throughout the duration of their treatment. Two participants reported that their 9- and10- year-old daughters exhibited behavioral problems at home.

Table 2

G1 Family Composition and Marital Status

Participant	Number of Children	Child Gender	Child Age at Dx [a]	Marital Status
Franny	3	F, M, F	10, 7, 3	Married
AmiAnn	2	F, M	9, 7	Married
Laucakes	2	F, M	8, 5	Divorced
Lindygirl	4	F, F, F, M	6, 9, 7, 3	Married
ShardyDee	2	M, M	7, 12	Divorced
Di-Mist	3	M, F, F	12, 8, 3	Married
Jessrun	1	M	8	Partnered
PaltoAll	1	F	10	Married
ToncaC	1	M	5	Widowed
Trumom	2	F, F	9, 12	Married

Note. [a] Diagnosis.

Six women identified as married, two as divorced, one as partnered, and one as widowed. The six married participants reported having conflicts with their spouses over differing parenting styles. The two divorced and one widowed participants reported on the challenges of single parenthood during their breast cancer experience, including lack of emotional and practical spousal support for participants and limited parental support for children.

G2 Demographics: Family Composition and Marital Status

As shown in Table 3, the family composition of G2 included 1-5 children, with the ages of children at the time of participant diagnosis and treatment ranging from 2-16 years old. One participant reported that having five children made parenting difficult throughout her cancer

experience and noted the complexities of dealing with school-age, pre-teen, and teenage personalities and emotional needs. G2 children consisted of 10 females and 11 males.

Table 3

*G2 Family C*omposition and Marital Status

Participant	Number of Children	Child Gender	Child Age at Dx [a]	Marital Status
AnabyU	1	M	11	Married
Kathmomdo	2	M, F	13, 10	Married
Marly Girl	2	F, F	14, 10	Married
Ma-Tree	5	M, F, F, M, M	16, 14, 11, 9, 6	Divorced
Patti Bear	1	F	4	Married
Cherrylady	1	M	12	Widowed
Proud Mama	1	F	2	Married
Larkylady	4	F, M, M, M	9, 6, 6, 3	Married
Rosebuds	2	F, M	6, 5	Married
Sassymom	3	M, F, M	16, 14, 11	Widowed

Note. [a] Diagnosis.

Four participants recalled behavioral problems occurring with their 6-to 11-year-old sons at home and while in school. Three participants recalled behavioral problems with their 10-to 14-year-old daughters while in school and at home. Seven women identified as married, two as widowed and single, one as divorced. Divorced and widowed participants recalled the challenges of single parenting throughout their cancer experience, including not having a spouse for emotional support or to help guide the children as a unified front.

Comparison of G1 and G2 Demographic Data

Women in both groups with sons aged 5 to 11 years at the time of diagnosis and treatment reported that their sons exhibited behavioral problems such as oppositional defiance toward teachers, poor sleeping patterns, and increased conflicts with siblings and school peers. G1-G2 participants reported that daughters aged 7 to 12 years were more curious and vocal about the breast cancer experience than their sons in the same age category. Girls talked more about

their mother's diagnosis and treatment than boys. Girls also experienced fewer emotional conflicts and behavioral problems at home and school than boys.

Women in both groups who identified as divorced, single, and/or widowed recalled feeling lonely. Participants in both groups reported having difficulty managing their children without assistance from a second parent. Unmarried or widowed women often found emotional support through former spouses, extended family members, close friends, colleagues, and specific members of their medical team. Participants with more than three children reported challenges of managing their children at the time of diagnosis and throughout treatment.

Primary and Secondary Methods of Coping Before Breast Cancer Diagnosis

Before their breast cancer diagnosis, 50% of G1 participants and 60% of G2 participants reported using a problem-focused strategy as a primary method of managing stress. A problem-focused approach to stress includes a logical plan of action to address complex problems. By using this practical approach to confront adversity, mothers also decreased the anxiety associated with specific issues and concerns. Members of both groups agreed that problem-focused coping helped them manage very stressful situations before diagnosis.

Thirty percent of G1 participants and 20% of G2 participants recalled using reactive coping (a maladaptive emotion-focused approach) to manage stress prior to diagnosis. Reactive coping includes immediate, knee-jerk responses to stress. Unlike a proactive and problem-focused approach to managing stress, mothers using the emotion-focused approach focused primarily on the difficulties of situations. Before diagnosis, 20% of both groups reported using a combination of problem- and emotion-focused methods to manage stress.

Both groups reported that personal relationships helped them manage adversity and stressful life events. Connecting with others was an important part of handling stress. Social

support systems included spouses, children, specific family members, and friends (see Appendix A). Several participants in each group considered colleagues to be part of their support system. Participants from both groups also included fulfilling activities as sources of managing stress. Activities included family events, religious gatherings, physical recreation, travel, etc. All participants agreed that fellowship and/or participation with others enhanced these activities.

Reactions to Breast Cancer Diagnosis

As shown in Table 4, when asked about their initial reaction to their breast cancer diagnosis, 70% of G1 participants recalled a combination of fear and panic, while 20% reported a combination of shock and grief. ShardyDee (G1) recalled having difficulty accepting the diagnosis and experienced a combination of anger and denial. She associated her denial of her breast cancer diagnosis with the fact that she did not have a family history and reflected on the untimeliness of the diagnosis. With emotional intensity, ShardyDee stated:

> I *really* got myself stuck on thinking I was free and clear since we had no family history of breast cancer. Then to think it [breast cancer diagnosis] came at the worst time ever! Life was going along great, all was well in [ShardyDee] the world up 'til then and I just wouldn't have that shit. Oh, Lord, did I get a hard dose of reality!

Table 4

Comparison of G1- G2 Reactions to Breast Cancer Diagnosis

Reaction(s)	Frequency of G1 Responses	Frequency of G2 Responses
Fear and Panic	7 (70%)	8 (80%)
Shock and Grief	2 (20%)	2 (20%)
Anger and Denial	1 (10%)	0 (0%)
Totals	10 (100%)	10 (100%)

N=10 in each group

Several in G1 recalled grieving over the loss of their health and physical changes to their body, such as mastectomies. Members of G1 thought they had a slim chance of developing breast cancer because they did not have a family history of the disease. Three women in G1 recalled *brief* feelings of anger and/or denial about their breast cancer diagnosis. G1 members believed that maintaining a stringent healthy lifestyle involving diet, exercise, and limiting/abstaining from alcohol and tobacco products would minimize the risk of getting breast cancer.

When asked about their emotional reactions to a breast cancer diagnosis, 80% of G2 participants reported a combination of fear and panic, while 20% reported a combination of shock and grief (see Table 4). Eight women recalled grieving the loss of their health. These same eight women also recalled grieving over the devastating physical effects of the breast cancer that would permanently disfigure and scar their body. Three women reported feeling shock despite their family histories and genetic predisposition. For instance, Larkylady reflectively commented:

> I was in shock for a very brief time, but fear took over! I was trembling. I had a small panic attack and just wanted to run, run, and run. I was so heart broken when I realized no matter how much I took care of myself, it [breast cancer] got me! It was like evil won and good died! I felt like my body betrayed me, as ridiculous as that may sound. Days after the doctor confirmed breast cancer I went into grieving overdrive. I felt defeated and very, very sad.

G1-G2 Coping at the Time of Diagnosis

At the time of diagnosis, 70% of G1 participants recalled using an emotion-focused approach to cope with the diagnosis, while 30% reported using a problem-focused approach to cope with the diagnosis. One participant in G1 recalled using a combination of emotion- and avoidant-focused coping to manage the emotional impact of the diagnosis. To help manage the emotional effects of diagnosis, 70% of G1 women relied on family members and friends. Despite the intensity of emotions, most in G1 recalled being focused on the care of their children. Thirty percent of G1 included their medical teams as significant support systems at the time of initial diagnosis. Several participants in G1 thought that nurses and social workers exhibited a high degree of empathy and understanding. All participants in G1 agreed that the social workers provided the most time for processing the psychological and psychosocial impact of the breast cancer diagnosis.

At the time of diagnosis, 60% of G2 participants recalled using an emotion-focused approach to cope with the diagnosis, while 30% reported using a problem-focused approach to cope with the diagnosis. One woman in G2 recalled using a combination of emotion- and avoidant-focused coping to manage the emotional impact of the diagnosis. To help manage the emotional effects of diagnosis, 60% of G2 relied on family members and friends. As with participants in G1, despite the intensity of emotions, most participants in G2 recalled being focused on the care of their children. Forty percent of G2 participants included their medical teams as a significant support system at the time of initial diagnosis. Several women in G2 thought that nurses and social workers exhibited a high degree of empathy and understanding. All women in G2 agreed that the social workers were able to provide the most time for processing the psychological and psychosocial impact of the breast cancer diagnosis.

Reactions to Breast Cancer Stage

In Table 5, I ranked data according to women's accounts of their initial reactions to their breast cancer stage. Eighty percent of G1 participants reported a combination of relief and hope as their primary response to their breast cancer stage. Twenty percent recalled feeling confused and indifferent about their stage; these same women believed that the diagnosis itself was enough information for them. For this 20%, although they knew it was important for the type of treatment required, the meaning of breast cancer stage was not clear at first. Several participants in G1 reported feeling somewhat anxious over staging after hearing other breast cancer survivors from their support group speak about their own experiences.

AmiAnn (G1) reflectively commented:

> In my group, women were from stage 0 to late stage 2. I remember worrying about whether the surgeon and the pathologist were wrong about my stage. I remember panicking about having a later stage of cancer even though my doctors reassured me I was stage IA.

Lindygirl (G1) added:

> I asked one of the nurses at the cancer center if this could have also been my case. She told me to speak with my doctor who stated that she was as certain as can be my stage was correct. She also said that cancer stage was only useful for determining the extent of disease and planning a course of treatment.

Table 5

*G1-G2 Comp*arison of Reaction(s) to Breast Cancer Stage

Initial Reaction(s)	Frequency of G1 Responses	Frequency of G2 Responses

Relief/Hope	8 (80%)	6 (60%)
Confusion/Indifference	2 (20%)	2 (20%)
Hopelessness/Despair	0 (0%)	2 (20%)
Totals	10 (100%)	10 (100%)

N=10 in each group

Sixty percent of G2 women reported feeling a combination of relief and hope. Twenty percent reported a combination of confusion and indifference about their stage, while 20% recalled feelings of hopelessness and despair. Marly Girl and Rosebuds felt terror after hearing from late-stage cancer survivors, as they, too, were initially diagnosed with stage IIB breast cancer. The women from G2 had heard mixed opinions about the purpose and use of cancer staging. Moreover, these participants had known they had breast cancer for weeks prior to receiving confirmation of stage. These women shared experiences of high anxiety while waiting for confirmation of staging. AnabyU (G2) explained:

> When the doctor first told me I had breast cancer, he said they were not sure of the prognosis, and I would have to wait until the surgery. I decided then to focus on the fact that I had breast cancer. Knowing the stage was no longer as important as just knowing I needed to get this monster out of me!

ProudMama (G2) added,

> At first, I let go of the whole stage thing because my surgeon said patients often draw their own conclusions about life expectancy when they hear their stage. I became indifferent to it. Then, after having to wait for weeks for final confirmation of my stage, I broke down and became highly anxious. It was a real killer!

G1-G2 Coping at the Time of Staging

At the time of staging, 80% of G1 participants recalled using an emotion-focused approach to coping with the stage of breast cancer. In addition, 10% of G1 participants reported using a problem-focused approach to coping with the stage of breast cancer, while 10% recalled using a combination of emotion- and avoidant-focused coping to manage the emotional impact of staging. To help them cope with staging, 60% of G1women used the medical team and a breast cancer support group to manage breast cancer stage-related concerns. The women of G1 relied on the medical team for clinical information pertaining to staging, while a support group helped them cope with the emotional stress of waiting for stage confirmation following the initial surgical procedure. Once doctors determined their stage, the G1 women could discuss fears and concerns with their group. Ten percent of G1 participants recalled using family and friends as primary supports to help them deal with pre-staging and staging anxiety.

At the time of staging, 80% of G2 participants recalled using an emotion-focused approach to coping with the stage of breast cancer, while 20% used a problem-focused approach. To help them cope with staging, 80% of G2 women used the medical team and a breast cancer support group to manage breast cancer stage-related concerns. All of the G2 participants relied on the medical team for clinical information pertaining to staging. In addition, a support group helped the G2 women cope with the emotional stress of waiting for stage confirmation following

their initial surgical procedure. Once doctors determined their stages, the women could discuss fears and concerns with the group. Twenty percent of G2 participants recalled using family and friends as primary supports to help them deal with pre-staging and staging anxiety.

G1-G2 Coping Throughout Treatment

Throughout treatment, 50% of G1 participants used emotion-focused coping. Thirty percent of this group reported that they were often too debilitated from the side effects of treatment and often limited their contact with other people. During treatment cycles, 70% recalled wanting to spend more time with their children than with people from any other significant relationship. Despite physical and psychological challenges faced during treatment, 20% used a combination of emotion- and problem-focused coping as a method of maintaining some control over their medical care and parenting skills.

Throughout treatment for G2 women, 60% used emotion-focused coping. Thirty percent reported they were often too debilitated from the side effects of treatment and often limited their contact with other people. During treatment cycles, 70% of G2 participants recalled wanting to spend more time with their children than with people from any other significant relationship. Despite physical and psychological challenges faced during treatment, 10% of G2 women used a combination of emotion- and problem-focused coping as a method of maintaining some control over their medical care and parenting skills.

Half of G1 and 60% of G2 participants reported receiving a combination of support from family, friends, and the medical team throughout treatment. Thirty percent of G1 and 40% of G2 participants recalled using family and friends as dominant supports throughout treatment. Two women in G1 thought the medical team and support group provided them with the most support.

G1-G2 Post-Treatment Coping

In the G1 group, six women increased problem-focused strategies more often following cancer treatment. Participants found that this method of coping helped manage stress-related situations. One woman, however, thought a problem-focused strategy was unrealistic. ShardyDee thought her psychological and emotional disposition prevented her from being able to use logical methods of coping. Several believed that their breast cancer and treatment experiences made them stronger and more resilient. Apart from Jessrun, the women's breast cancer experiences inspired an authentic desire for owning and facing adversity with determination and resolution.

Once treatment was completed, 40% of G1 participants used the medical team and support group as primary methods to help manage post-treatment stress. Thirty percent thought a combination of family, friends, and medical team helped them cope best with post-treatment concerns. Three women thought family and friends helped them deal with the emotional and social anxiety resulting from breast cancer survivorship, with several remarking on how their child's ability to cope with the crisis of breast cancer inspired hope and deep gratitude.

In G2, seven women reported using problem-focused strategies more often following cancer treatment. This method of coping helped them manage stress-related situations. Nine attributed their ability to manage stress more effectively to surviving cancer. Apart from Larkylady, the women's breast cancer experience also inspired an authentic desire for owning and facing adversity with determination and resolution.

In G2, once treatment ended, 50% of participants used the medical team and support group as primary methods to help manage post-treatment stress, while 50% thought a combination of family, friends, and medical team helped them cope best. Several women thought family and friends helped them deal with the emotional and social anxiety resulting from breast

cancer survivorship, while several found their children to be a source of encouragement and hope. Nine women were inspired by their child's empathy and cooperation throughout the cancer experience.

A month after their final treatment, 70% of G1 participants and 90% G2 participants recalled using problem-focused coping strategies to manage stress. Twenty percent of G1 and 10% of G2 recalled using a combination of emotion- and problem-focused strategies to manage stress. One woman in G1 reported using a problem-focused approach to manage stress.

AnabyU (G2) captured the experience thusly:

> Before the breast cancer diagnosis, I let my anxiety rule over me. I would become so fearful of so many things that *could* go wrong. Breast cancer and all that time in treatment forced me to get a better handle on my fears of the unknown. I guess you could say that having to deal with a life-threatening illness opened me up to realizing that many of the things I worry about are nonsense. So much less worry now!

ProudMama (G2) emotionally commented,

> It's a bit strange really. I find myself worried from time to time about recurrence, but ever since the diagnosis and getting through the radiation and chemo, I believe I can conquer most anything. I really feel that having had and survived breast cancer has significantly boosted my self-confidence!

Primary and Secondary Styles and Methods of Communication

Communication Before Diagnosis

Participants from both G1and G2 recalled that their methods of communication changed after being diagnosed with breast cancer. Before their diagnosis, 50% of G1participants and 70% of G2participants reported using combinations of direct, open, and indirect styles of communication as primary modes of communication. Forty percent of G1 and 30% of G2 reported using a combination of direct, open, and third-party communication with their children before diagnosis. One woman in G1 reported using a combination of third-party and avoidant communication methods before her breast cancer diagnosis.

Both groups described their use of communication as having an intentional focus and precise understanding between them and their children. Several reported using direct communication, especially at times when their children required corrective action due to

interpersonal conflicts with siblings, behavioral problems in school, etc. Both groups described indirect and/or third-party communication when communicating with their children through a spouse, family members, teachers, emails, and phone or text. Several described indirect communications, such as body language, as less literal and not as clear as direct communication.

Both groups described the use of open communication as a frequent practice for expressing thoughts and emotions about relevant, meaningful topics. Open communication allowed for an exchange of ideas and feelings that often resulted in resolution. Both groups found open communication as an effective method for bonding and gaining a better understanding of their children's moods or states of mind.

Lindygirl (G1) reported regular use of avoidant communication with her children before diagnosis. She recalled using avoidant communication as a method for managing the emotional stress that accompanied disappointing and emotionally provocative topics, such as cancelling events, establishing personal boundaries, limiting use of electronic equipment, etc. No one from G2 recalled using avoidant communication with their children before diagnosis.

Both groups shared a mutual understanding and use of communication with their children before diagnosis. Both described communication as a basic, utilitarian method of relaying and exchanging ideas, thoughts, and feelings. Prior to diagnosis, both groups managed communication by initiating discussions with their children for practical purposes.

The women in G1and G2 used direct communication and third-party communication as primary methods of communication with their children before their diagnosis. Both also reported methods of indirect and open communication. Despite the use of indirect communication, G2 participants found this approach least favorable as a means of interaction with their children.

Several women in G2 reported that indirect communication often leads to confusion and misinterpretation of thoughts and feelings between mothers and their children.

Communication at the Time of Diagnosis

At the time of diagnosis, 80% of participants in G1 reported using a third-party approach when they told their children of their breast cancer. One participant chose a combination of third-party and open communication when she informed her children of her diagnosis, while another used a combination of third-party and avoidant communication. Except for Franny, women informed their children at the recommended time; Franny chose not to tell her daughters until after her procedure.

In G2, at the time of diagnosis, 90% of participants reported using a third-party approach when they told their children of their breast cancer. One chose a combination of third-party and open communication when she informed her children of her diagnosis. Patti Bear and ProudMama informed their children at the recommended time, while Franny chose not to tell her daughters until after her procedure. Patti Bear and her spouse told their 4-year-old one week before the mastectomy by using an age-appropriate story narrative. ProudMama and her wife used their child's age and developmental needs to guide communication about the hospitalization.

Medical teams encouraged both groups to initiate a discussion with their children at least two weeks before their initial surgical procedure. Both groups believed that the sensitive nature of the information was too emotionally taxing to manage communication alone. They elicited support from spouses, family members, close friends, and/or members of their medical team to help them reveal the diagnosis to their children.

Both groups used familiar communication styles when they told their children about their diagnosis. Eighty percent of G1 and 90% of G2 reported using pre-diagnosis communication styles in conjunction with other forms of communication when telling their children of the breast cancer. No one in G1or G2 significantly changed their communication style at the time of diagnosis, although communication style at the time of diagnosis was augmented to meet the emotional needs of mothers who were revealing a traumatic event.

Communication at the Time of Staging

More than half of the women in G1 recalled how their physician revealed their stage to them weeks after the initial surgical procedure. Seventy percent remembered feeling too anxious about the results of the pathology report and chose not to talk about it. At the time of staging confirmation, most reported they did not share or discuss staging with their children, believing that it might be too confusing. Most women decided to discuss matters of breast cancer stage with members of their oncology team. More than half of the G1 women used their breast cancer support groups to process thoughts and feelings about cancer stage. G1 women also used a combination of third-party and avoidant styles of communication at the time of staging.

In G2, more than half of the participants recalled how their physician revealed their stage to them weeks after the initial surgical procedure. Ninety percent of the women in G2 remembered feeling too anxious about the results of the pathology report and chose not to talk about it. At the time of staging confirmation, most participants reported that they did not share or discuss staging with their children, with several believing it might be too confusing for their children. These women decided to discuss matters of breast cancer stage with members of their oncology team. More than half of the women in each group also used their breast cancer support

groups to process thoughts and feelings about stage. Women in G2 used a combination of third-party-avoidant styles of communication at time of staging.

Most of the women in G1 and all of the women in G2 thought communication with their children about breast cancer stage was irrelevant. Both groups were often ambivalent about their cancer stage and more focused on the diagnosis and treatment protocols. Several women in G1and G2 withheld stage information from their children and others, believing staging was too complex and confusing of a subject. Both groups reported concerns over assumptions and misinterpretations about staging and chose to limit discussions about staging to the breast center. Most women found their medical teams and support groups to be helpful in managing questions and concerns about staging.

Communication Throughout Treatment

Throughout breast cancer treatment, 70% of the participants in G1 used a combination of third-party and indirect styles of communication. Two women used a combination of third-party and open communication during treatment, while one used a combination of third-party and avoidant communication. This group recalled experiences of moderate to severe physical discomfort after surgical intervention. Their recall included wrenching tissue and muscle pain, soreness, and fatigue after surgery. They also reported psychological and emotional distress from scarring and/or the loss of their breast(s). Only Franny ascribed post-surgical discomfort and treatment side effects to changes in communication patterns with her children.

Throughout breast cancer treatment in G2, 80% of participants used a combination of third-party and indirect styles of communication during treatment. One woman used a combination of third-party and open communication, while another used a combination of third-

party and avoidant communication. G2 women recalled moderate to severe physical discomfort after surgical intervention.

Despite breast cancer stage, both groups shared similar psychological and emotional responses during treatment, such as loss, hopelessness, anger, and helplessness. These experiences included emotional and psychological responses to surgical procedures and the harsh side effects from chemotherapy and radiation. Furthermore, these reactions to treatment often affected communication patterns with their children. Both groups found it difficult to use open and direct communication methods during treatment due to physical, psychological, and emotional limitations.

Women in both groups often used third-party, indirect, and avoidant methods of communication throughout their treatment. These women reported having to use such methods because they were too ill to consistently manage direct, open communication patterns. Several participants in G2 reported using open communication when possible; however, these same women also reported difficulty using open communication while also managing side effects of treatment.

Post-Treatment Communication Patterns

At least one month after their last round of radiation/chemotherapy, 80% of G1 women used a combination of direct, open, and third-party communication styles. Twenty percent used a combination of direct, open, and indirect styles of communication. Several women used third-party communication when a direct approach was difficult or not possible. These women used indirect methods of communication when under pressure and/or when they were not sure about something. None of the women in G1 reported use of avoidant communication styles after their last treatment.

At least one month after their last round of radiation/chemotherapy, 60% of G2 participants used a combination of direct, open, and third-party communication styles. Forty percent used a combination of direct, open, and indirect styles of communication, while several used third-party communication when a direct approach was difficult or not possible. These women used indirect methods of communication when under pressure and/or when they were not sure about something. They did not report use of avoidant communication styles after their last treatment.

Both groups reported no longer using avoidant communication post-treatment. Several women from each group reported using proactive, direct and open communication styles to communicate with their children after their last treatment. Women reported using less indirect methods of communication, but still used third-party methods when required.

Jessrun (G1) and Cherrylady (G2) continued using indirect communication methods. Both women reported that their children often asked questions about topics such as sexuality, interpersonal conflicts, and marital problems that sometimes required limited sharing of knowledge and/or redirection. Several women in G1 and G2 reported that they spent more time communicating with their children since breast cancer treatment. Both groups spent more time listening to their children, and their children listened more intently to what was being said during mother-child interactions.

Participants from G1and G2 reported feeling inspired by their breast cancer experiences. One and a half months after their final chemotherapy cycle, both groups felt physically and psychologically ready to face their lives head on. The women believed they had a new lease on life. Several women in G2 reported having new insights about wanting to be more patient as

mothers. Those same women also gained a new perspective about communicating more openly and directly with their children.

Apart from ToncaC (G2), all participants reported using a more consistent direct approach to communication after their last chemo treatment. Eight women in G1 reported using an open approach to communication. All recalled using third-party communication, such as texts, emails, or older siblings, when a direct approach was difficult or not possible. Those same women also reported using a third-party approach when confirming and/or reaffirming important information. One woman in G2 reported using indirect communication with her 9-year-old son; Cherrylady used indirect communication when her son was unruly or asked questions she was not prepared to answer. Women from G2 did not report use of avoidant communication styles after their last chemo cycle.

Descriptive Themes

Theme 1. Relationships as a Mediating Factor for Coping

Coping Mechanisms Before Breast Cancer Diagnosis

Several women in both groups identified that having significant relationships, whether it be spouses, children, family, friends or colleagues, helped them cope with adversity and stress before their breast cancer diagnosis. They thought that individual connections with others helped ease the psychological and emotional stress that accompanied traumatic events from the past. Several women recalled the importance of having had someone to talk to during difficult situations, such as miscarriages, deaths, marital problems, etc. Many thought that having significant, meaningful relationships included the giving and sharing of time. They reported that intimate, close relationships validated thoughts and feelings during difficult times.

Several women in both groups found that participating in meaningful activities, such as therapy, meditation groups, church groups, etc., helped them to manage adversity and stress before diagnosis and treatment. All of the women described participation in meaningful activities as a method of taking a break from personal problems. Three women from G1 and five from G2 recalled how participation in social and/or supportive environments provided comfort and reduced stress. In G1, 60% of participants chose to be part of something greater than themselves in the service of others via a group or organization when confronted with challenges. In G2, 30% of participants found meaningful activities through service, while 20% reported greater benefits from individual and/or group therapy.

Three women from G1 and four from G2 reported their religion and/or spiritual practices as methods of coping with stress before diagnosis and treatment. All described their religious and/or spiritual beliefs as important aspects of managing uncertainty. They believed that their religion and its practices helped them to make sense out of difficulties and tragedies they experienced. In G1, 50% of participants reported that a belief in a higher power increased their ability to manage the darker, more difficult aspects of their lives. In G2, 60% of participants reported belief in a higher power, but half of those participants identified as spiritual and not religious.

Outlier

ProudMama (G2) identified her personality type as the primary reason for how she coped with stress before diagnosis. She also thought familial conditioning and tragic events before breast cancer honed her coping skills. Before breast cancer, ProudMama dealt with firsthand experiences of adversity. She thought these experiences helped prepare her for managing the breast cancer experience.

ProudMama emotionally reminisced:

I think and believe in my heart that my mom's death, when I was 7 laid the foundation for handling whatever life throws at me. Mom's death was very, very tough on me. Oh, yes, and let's not forget about the numerous spinal surgeries from a fall that almost paralyzed me.

Coping Mechanisms at the Time of Diagnosis

Several women in both groups reported that, at the time of diagnosis, positive relationships with spouses, children, families, and friends helped them deal with the shock and grief of the diagnosis. Those women recalled thinking about their spouse and children when diagnosed and described their spouses and children as primary, significant support. Those without spouses and/or with unsupportive ex-spouses recalled thinking of their children at the time of diagnosis. Both groups described having mixed emotions; they needed their children's support for comfort and safety, but also felt the need to shield them from the horror of breast cancer. All the women recalled that knowing that they had a loving, caring spouse and/or children helped ease some of the shock and grief.

Women from both groups reported the importance of their medical teams as an important part of coping at the time of diagnosis. All recalled having thoughts and feelings of relief stemming from their belief that their teams of physicians, nurses, and social workers would help manage the medical, psychological, and emotional aspects of their breast cancer experience. Eight women from G1 and all women from G2 remembered feeling secure and reassured that their teams would help them fight the breast cancer battle. All reported that they had to believe in their teams, particularly in their surgeons and oncologists. In addition, all believed that consistent

communication with and among all team members helped them cope with their diagnosis throughout treatment.

Participants from G1and G2 found it important and beneficial to reach out to other women who shared a similar experience. They believed that personal testimonies from peers who walked the talk, so to speak, helped allay some of their fears. All found that weekly face-to face support groups gave them opportunities to express fears, concerns, joys, and hopes. Several women in G1 and G2 reported using the groups to discuss concerns related to family members, as well as challenges with their medical teams.

Coping Mechanisms at Time of Staging

Participants understood that doctors used cancer stage to determine the course of treatment and that stage does not translate to prognosis. They reported that knowing their stage was not as emotionally intense as their initial diagnosis. One woman in G1 reported that she felt despair when diagnosed with stage IB breast cancer. Two from G2 reported despair and hopelessness.

Despite their overall indifference to staging, both groups reported being grateful and relieved that their breast cancer doctors found the disease and treated them at an early stage. Eight G1 women and 10 G2 women recalled feeling hopeful about their prognosis. Lindygirl and ToncaC fromG1) remembered feeling pessimistic about the possibility of recurrence, despite receiving confirmation that they were cancer-free.

ProudMama (G2) believed that she remained fixated on the possibility of recurrence, but peers in her support group helped her to focus more on having survived breast cancer and on continuing to thrive. Several women in G1and G2 chose to use knowledge of their cancer stage

solely for medical purposes. These same participants relied on support from their medical teams to manage concerns related to stage.

Outlier

Cherrylady (G2) recalled being obsessed with her breast cancer stage. She experienced panic attacks and many sleepless nights thinking about recurrence. Cherrylady would often refrain from sharing her fears in group. She reflectively explained:

> I always thought the other ladies in my group handled it (stage) with more ease than me. I just remember always having in my head that stage II was not far from stage III and how do they (doctors) *really* know I was not III instead of II? I got so disgusted I just asked her (nurse practitioner) for an anti-anxiety med.

Coping Mechanisms Throughout Treatment

Women from both groups recalled the importance of maintaining their parental identity throughout treatment. Several of them remembered how daily involvement with their children boosted morale and kept them emotionally grounded. In G1, 70% of the participants believed that their maternal role motivated them to manage the physical, psychological, and emotional impacts of treatment. In G2, 90% of the participants reported that remaining an active parent throughout treatment helped keep their dignity intact. Of the 70% in G1 who identified the importance of maintaining the maternal role, 60% believed that their children also benefitted from active parenting throughout treatment. Of the 90% in G2 who emphasized the importance of active parenting, 80% stated that their children felt that daily interactions were important, even if the length or frequency of those interactions was reduced.

Women from both groups recalled that having an attitude of openness throughout treatment helped them to manage frustration and physical pain. Several of them remembered the

importance of reflection and using time to nurture the desire to learn how to become more patient with their situations. In G1, 60% of participants stated that they used their treatment as a time for attaining insights about their personality flaws. In G2, 60% of participants stated that time during treatment forced them to face the often-ignored inner silence.

Several women in G1and G2 reported that they surrendered to the overwhelming physical, psychological, and emotional demands of treatment. In G1, 40% recalled that, before their second round of radiation, they accepted the effects of the treatment without fear and concern. Of this 40%, three stated that it was not about giving up but rather about coming to terms with what needed to be done.

In G2, 60% of participants decided after their second round of chemotherapy to stop fighting fears and concerns related to the side effects of treatment. Of this 60%, three stated that resisting and/or complaining about treatment side effects increased stress, so they decided to let go and trust the treatment process. Both groups believed that letting go and allowing time for effective treatment helped them to cope during the treatment process. By letting go of control and worry throughout treatment, 90% of G1participants and 100% of G2 participants held firmly to thoughts and images of feeling better and conquering cancer.

Women from both groups reported that treatment introduced them to self-acceptance and an ability to be more patient with themselves. All used their newfound skills to cope with the physical, psychological, and emotional impact of treatment. Three women in G1 and five women in G2 shared their ideas and techniques with peers, as well as with others willing to listen and learn.

Outlier

Unlike most participants, Marly Girl (G2) stated that she needed to be alone throughout treatment. She often found no comfort from others. Furthermore, she could not rise above the anger and despair that often kept her isolated. Marly Girl emotionally responded:

> It's like I wanted to vanish and die one minute then make the world explode in another! I have to be honest, that shit (chemotherapy) messed with by whole damn mind and body. I didn't even want my daughters around me (paused and began to cry).

Post-Treatment and Survivorship Coping Mechanisms

Within a month and a half after their final treatment, 70% of participants from G1 reported that they felt as though life began again. Of that 70%, 60% believed that they had an opportunity and responsibility to share their breast cancer experience with others. Two to three months after their final treatment, 60% of G2 women recalled believing and feeling as though they had a second chance at life. Like the women in G1, those in G2 understood their survival of breast cancer as an obligation to appreciate life, while respecting what they had endured. Both groups had not taken for granted their early stage diagnosis and were fully aware of what *could* have been.

All reported that the cancer experience helped them accept uncertainty with greater ease. In G1, 80% of the participants believed that they were psychologically and emotionally stronger since diagnosis and treatment. In G2, 70% of the participants believed that they were psychologically and emotionally stronger since diagnosis and treatment. Two women in G2 reported that since their last treatment, they often worried about recurrence, despite a good prognosis.

All of the women emphasized a greater awareness of their emotional bonds with their children and described how their children's strength and resilience throughout the cancer

experience inspired them to be better mothers. Since diagnosis and treatment, all of the women in G1 remarked that they had come to appreciate interactions with their children. Several in G1 also found it easier to manage difficult children. In G2, 80% of participants recalled having a deeper appreciation of interactions with their children.

Like G1, several women in G2 believed and felt that since diagnosis and treatment, they were more patient and understanding with their behaviorally challenged children. All of them recalled that since diagnosis and treatment, relationships with their children were more open and stable due to increased communication; this increased communication strengthened their mother-child bond.

All of the women thought that the breast cancer experience motivated them to be fully present and live more in the moment. In G1, 50% of the participants stated that post-diagnosis and treatment, they insisted on being expressive and action-oriented by attaining personal goals without decreased self-doubt and/or fear. In G2, 60% of participants fostered a more assertive approach to self-care by no longer placing the needs of others before their own. Of this 60%, 40% attributed being more direct with people and less fearful of confrontation to their cancer experience.

All of the women used their newly honed skills to confront their fears and concerns about the uncertainties of breast cancer recurrence. In G1, 70% of the participants stated that the cancer experience had prepared them well enough to manage the emotional stress of recurrence. In G2, 90% thought the cancer experience would help them psychologically and emotionally survive other traumatic events. Of that 90%, 70% stated that the death of a daughter and/or son could not be included in the tragic events.

Theme 2. Communication as a Source of Emotional Strength and Survival

Communication Before Diagnosis

Both groups described communication patterns prior to their breast cancer diagnosis as a practical means of expressing and exchanging thoughts, ideas, and feelings with their children. Interactions with their children before their diagnosis were useful in exchanging thoughts and ideas about critical issues and/or concerns about health or general well-being. Both used communication for instruction of needs and tasks pertaining to the activities and responsibilities of daily living such as chores, homework, caring for younger siblings, etc.

All of the participants used communication as a primary source of gathering and sharing information as a means of keeping the family organized. Several described effective communications as a primary housekeeping tool required for order and control in the home. Three participants in G1 and four in G2 reported a hierarchy of communication within their homes. Those same women described themselves as primary sources for the dissemination, interpretation, and articulation of crucial familial information.

All of the survivors described communication as a method of maintaining relational connections through emotion. They used both verbal communication and physical actions such as hugging and kissing to demonstrate affection and to establish emotional bonds with their children. They believed that verbal interactions were insufficient to emotionally connect with their children.

Communication at the Time of Diagnosis

All of the survivors recalled their rationales for not revealing their diagnosis to their children. They believed that no mother should have to tell her children that their parent is sick and so initially refused to inform their children; this refusal stemmed from a place of parental

concern. Both groups tried to resist having to tell their children, fearing that their children would not be able to manage the news.

Both groups believed that the uncertainty of their diagnosis complicated communication with their children. They knew that their children would have questions about their illness, but they were not equipped with the information needed. They believed that the uncertainty of their breast cancer rendered them powerless over whether they could answer their children's questions. They were accustomed to having answers to their children's questions prior to their diagnosis of breast cancer. Their emotions at the time of diagnosis often overwhelmed their verbal ability.

ProudMama (G2) captured the experience thusly:

> I remember many days not wanting to talk, but just cry, cry, and cry. No words, silence, and sometimes tears were enough (began to cry).

Outlier

Unlike most participants, Franny (G1) was not overwhelmed by fear and/or grief at the time of diagnosis. She wanted to share and discuss her diagnosis and surgical procedure with anyone who might be interested. Franny spoke with two of her children openly about the diagnosis. Franny used her initial fear of early-stage diagnosis/stage as motivation to educate other women about the importance of early detection. Franny exuberantly shared:

> I was and am one of the lucky ones. Not only was it (tumor) caught early, but I did not have to go through loads of radiation and no chemo. This was a wake-up call for me and my mission is to help other women, especially the moms, who may be at risk for breast cancer.

Communication at Time of Staging

Several survivors spoke of limiting their communication about breast cancer stage to their surgeons and oncologists. Fifty percent of G1 participants and 70% of G2 participants addressed staging concerns in their support groups. In G2, 70% of the women relied on their support groups to discuss stage-related frustrations and fears. All of the women agreed that sharing thoughts and feelings with anyone other than members of the medical team or other survivors was not beneficial. Twenty percent of G1 participants and 90% of G2 thought that discussing stage with loved ones would create confusion and unnecessary concern.

Communication Throughout Treatment

All of the women recalled thoughts of helplessness and uselessness when communicating with their children during breast cancer treatment. Side effects from radiation and/or chemotherapy limited their ability to focus, maintain memory, and manage in-depth conversations. They reported that breast cancer treatment hijacked their ability and desire to communicate with everyone, but this limitation was emotionally painful when it came to their children.

The physical and psychological harshness of treatment often resulted in a marked decrease of affective involvement among participants, their spouse, and children. Paradoxically, affective involvement increased among children. Participants remembered how their children demonstrated a spirit of cooperation and sensitivity toward siblings, specifically younger siblings. Spouses and other family members told participants that children often exhibited genuine interest in helping and wanting to be involved in caring for their sick parent.

The survivors recalled coming to terms with their treatment and chose to use the time to hone communication by being more reflective and by journaling their thoughts and feelings.

Peers and social worker staff encouraged them to use journaling as a tool to release frustration and to log thoughts and ideas. Participants recalled sharing some journal entries with their children and believed that their journals were an important, effective way of communicating with their children during treatment.

At times throughout treatment, the women thought that third-party communication contributed to increased isolation and alienation from their children. They recalled having intense experiences of physical, psychological, and emotional separateness from their children throughout cancer treatment. Several women in both groups described their experience as being unnaturally cut off from an important source of life. To help minimize this isolation, the women used text, video, audio, SKYPE, and Snapchat to communicate throughout treatment. Several reminisced about their children teaching them how to use these various modes of communication. More than half of G2 participants reported that they used these teaching/ learning opportunities to bond with their children.

Post-Treatment Communication

The survivors reported feeling energized by their breast cancer experience. Following their final chemotherapy cycle, they began to feel physically and psychologically ready to use a direct communication approach with their children. Several women reported having a new appreciation for communicating with their children.

G1 participants recalled having more of an emphasis on the quality of communication, rather than on how much time they spent talking with their children. Four women spoke candidly about being more attentive to their children. They believed that the breast cancer experience helped them become more attuned to what their children had to say.

Except for Kathmomdo (G2), the women recalled having more of an emphasis on improving their listening skills. Seventy percent of participants in G1 believed that their breast cancer experience helped them become less focused on instant gratification. The women reported wanting to spend more time listening to their children than making assumptions and/or reacting. Eighty percent of participants in G2 reported that they wanted to be more validating toward their children. Both spoke of having more of an interest in directly communicating to their children how much they cared about their dreams, ideas, and opinions. Apart from Marly Girl (G2), women reported that they enjoyed communicating with their children more since the breast cancer experience.

Early-stage Breast Cancer Survivors Give Advice to Future Breast Cancer Survivor

All participants provided personal recommendations that might provide current and future breast cancer survivors with guidance and encouragement. Four themes prominently emerged from these recommendations. Several women responded openly and with notable conviction that possessing knowledge of their family medical history was important. Support from other early-stage breast cancer survivors ranked second as an essential part of managing anxiety and depression. All of the women agreed that it was important for them to help others understand the importance of maintaining the parental role throughout the cancer continuum. A majority of the survivors advocated for children of breast cancer survivors to participate in peer-oriented groups for emotional and social support.

Knowledge of Genetics and Family History

In G1, several participants strongly recommended that women learn about their family history of breast cancer, as well as other types of cancer. For 70% of participants, knowing their family history helped them make sense of the trauma they faced. In G2, 90% of participants

recommended that women learn about their family history and consider genetic screening for breast cancer and/or other cancers (BRCA1 and BRCA2). Of these 90%, 80% believed and felt that having knowledge about their family and genetic background helped clarify the reason for their diagnosis.

Both groups of women reported that having an awareness of family history and a knowledge of genetic predisposition to breast cancer motivated them to be more watchful of health concerns. Several stated that knowing their BRCA1or 2 status helped them and their oncologist make better-informed post-treatment medical decisions. The women agreed that the greatest benefit of knowing their family history and BRCA status was that it empowered them to initiate a plan for their children, should cancer-related health decisions be required in the future.

Peer Support

In G1, 60% of the participants suggested that mothers diagnosed with early-stage breast cancer participate in weekly face-to-face support group. In G2, 80% of participants suggested weekly in-person support groups. Of these, 40% recommended support groups specifically related to stage (stage IIA/IIB). Both groups recalled how they emotionally and socially benefitted from sharing fears about breast cancer, prognosis, staging, and treatment. Several also used the weekly forum to discuss parenting concerns. Weekly participation helped participants feel less alone and more understood.

Several participants highly recommended breast cancer support groups specifically for parents of young children and adolescents. In G1, 40% of the participants highly suggested ongoing, face-to-face support groups for mothers in remission. In G2, 90% of the participants

highly suggested continuance of in-person support until mothers no longer felt the need for group support.

Maintaining Parental Identity Throughout all Phases of Breast Cancer

All of the survivors unanimously agreed that a diagnosis of breast cancer and/or cancer treatment did not preclude them from being active parental figures. In G1, 90% of the participants recalled having to reinforce with spouses, family, and friends that active parenting throughout the cancer continuum helped them to manage anxiety and depression. In G2, all of the women remembered having to remind loved ones that a breast cancer diagnosis and treatment did not require a break from motherhood. Of these, 90% thought that maintaining their parental role at the time of diagnosis and throughout treatment validated their usefulness as a mother and helped them to cope with the psychological and emotional challenges of breast cancer diagnosis and treatment.

Self-Advocacy

All of the women agreed that mothers diagnosed with breast cancer need to learn to set boundaries. In G1, 60% of the participants stated that they wished they had set limits to what others expected of them as far as household responsibilities, social events, and work obligations. In G2, 90% of the participants recommended that mothers recognize the right and the need for self-care. All participants agreed on the importance of accepting physical, psychological, and emotional limitations throughout the cancer continuum.

Several women claimed that they had difficulty allowing themselves to be cared for by others and/or nurturing themselves. All realized that when they allowed others to care for them and/or initiated self-caring practices, such as wanting to be alone or delegating some responsibilities, they experienced a heightened mood and/or decreased physical fatigue. All of

the women highly recommended that mothers ensure consistent, open communication with members of their medical teams. Several women thought that if or when they confronted a breakdown in communication, they needed to be courageous and challenge any self-doubts and/or feelings of unworthiness. One participant in G2 suggested that women know their legal rights as a cancer patient and survivor.

Resources for Children to Help Them Cope with Mother's Breast Cancer

According to all participants, social workers from the Cancer Center initiated a discussion with them about a support group for their children. They recalled having memories of indifference toward the group idea, believing their children might not like or benefit from participation. Several participants signed their children up for at least one support group. Children who participated in weekly or bi-weekly support groups demonstrated significant improvements in behavioral problems and decreased absences from school. Of the G1 participants whose children participated, 60% recommended that mothers encourage their children to participate in a support group. Of the G2 participants whose children participated in a support group, 90% recommended a support group for children.

Summary

In this chapter, I presented the findings of the study. I analyzed audio transcripts from two groups of early breast cancer survivors. The first group (G1) consisted of 10 participants diagnosed with stage 0, IA, or IB breast cancer. The second (G2) consisted of 10 participants diagnosed with stage IIA or IIB breast cancer. I presented the findings in three sections: (a) coping mechanisms of early-stage breast cancer survivors, (b) communication patterns between early-stage breast cancer survivors and their children, and (c) survivors' advice to other mothers facing early-stage breast cancer. Each section corresponded with primary and secondary

responses about participants' experiences before diagnosis, at the time of diagnosis, during treatment, and post-treatment. Each section included descriptive themes captured by G1 and G2 participants throughout their breast cancer experience.

Data in the first part included participants' recollections, perceptions, and experiences of (a) coping strategies before diagnosis, (b) initial reaction(s) to diagnosis and coping with the diagnosis, (c) coping with breast cancer stage, (d) coping mechanisms during treatment, and (e) coping mechanisms post-treatment.

Prior to diagnosis, 50% of G1participants and 60% of G2 participants recalled using problem-focused coping as a primary strategy for managing stress. Among G1 participants, 30% used emotion-focused coping before diagnosis, as did 20% of G2 participants. At the time of diagnosis, 70% of G1 and 80% of G2 participants recalled experiencing initial reactions of fear and panic. Secondary reactions to the breast cancer diagnosis included a combination of shock and grief by 20% of G1 women and 20% of G2 women. At the time of diagnosis, 70% of G1 and 60% of G2 participants used emotion-focused coping to manage the stress of their diagnosis. Thirty percent from both groups used a problem-focused approach to manage stress. As for the initial reactions to staging, 80% of G1 and 60% of G2 participants shared a combination of relief and hope. Secondary combinations of confusion and indifference about staging occurred for 20% of both groups.

During treatment, 50% G1 and 60% G2 participants used an emotion-focused strategy, while 30% of both groups used avoidant coping strategies. Post-treatment strategies took the form or problem-focused strategies for 70% of G1 participants and 90% of G2 participants. Secondary post-treatment strategies included a combination of emotion- and problem-focused strategies among 20% of G1 and 10% of G2 participants.

Data in the second section included G1and G2 recollections, perceptions, and experiences of (a) communication with their children before their breast cancer diagnosis, (b) communication with their children at the time of diagnosis, (c) communication with their children during treatment, and (d) communication with their children post-treatment. Prior to diagnosis, 50% of G1 and 70% of G2 participants used a combination of direct, open, and indirect methods of communication. Secondary methods included the use of direct, open, and third-party methods among 40% of G1 women and 30% of G2 women.

At the time of diagnosis, 80% of G1 and 90% of G2 participants used third-party methods of communication with their children. As a secondary method of communication, 10% of G1 and 10% of G2 participants used a combination of third-party and open communication with their children at the time of diagnosis. During treatment, 70% of G1 and 80% of G2 participants used a combination of third-party and indirect methods of communication with their children. Secondary methods of communication included the use of third-party and open communication among 20% of G1 participants and 10% of G2 participants.

After their final treatment, 80% of G1 and 60% of G2 participants used a combination of direct, open, and third-party methods of communication with their children. As a secondary method of communication, 20% of G1 and 40% of G2 participants used a combination of direct, open, and indirect methods following their final treatment.

Data in the third section included two dominant themes. Theme 1 involved narratives describing initial reactions to breast cancer diagnosis and stage of breast cancer. Participants spoke about managing the psychological and emotional effects of diagnosis and stage. Furthermore, they gave accounts of how they coped with psychological and emotional stress (a) before diagnosis, (b) at the time of diagnosis, (c) at the time of staging, (d) during treatment, and

(e) post-treatment. Theme 2 included narratives associated with communication patterns between survivors and their children (a) before diagnosis, (b) at time of diagnosis, (c) at time of staging**,** (d) throughout treatment, and (e) post-treatment.

Data in the fourth part included advice from both groups for mothers diagnosed with early-stage breast cancer. For 90% of G1 and 100% of G2 participants, the primary recommendations included (a) the importance of knowing one's family history of cancer, (b) demanding open, consistent communication with medical teams, (c) joining a support group/linking children to their own support group, and (d) maintaining the parental (maternal) identity during all phases of the breast cancer continuum. In terms of secondary recommendations, 10% of G1 participants stressed the importance of (a) reaching out to breast cancer survivors early in the diagnosis and (b) knowing the legal rights of those with cancer.

Conclusion

Both groups similarly described the breast cancer experience as paradoxical. The diagnosis was traumatic, but in the long run, personal and interpersonal benefits occurred. Breast cancer treatments had deleterious effects on the women's physical, psychological, emotional, and social well-being. Despite their struggle, however, all breast cancer survivors learned to adapt to, and cope with, their diagnosis. All women managed communication at the time of diagnosis, during radiation treatment, chemotherapy, and post-chemotherapy. All continued to cope with the physical, psychological, emotional, and social implications of their breast cancer experience long after the completion of treatment.

Resulting from the trauma of early-stage breast cancer, all of the women reported positive, meaningful changes in communication styles with their children. All also found that the breast cancer experience precipitated a desire to learn from their child's coping and resilience as

a mechanism for motivation and hope. Furthermore, they refined pre-existent coping skills while honing new ones to improve communication and to cope with uncertainty and themes of survivorship.

In Chapter 5, I present (a) an interpretation of the findings, (b) limitations of the study, (c) recommendations for further research, (d) implications for positive social change, and (e) a conclusion.

Chapter 5: Summary, Conclusions, and Recommendations

Introduction

The overall purpose of this study was to understand the interrelationship among several variables, including cancer staging, communication patterns, and psychosocial coping among maternal breast cancer survivors. The units of analysis were the effects of early-stage breast cancer diagnosis, stage, and treatment on coping and communication patterns between mothers and their children. In the analysis, I sought to develop an in-depth understanding of how a mother's cancer stage affects coping and communication with her children.

Using a sample of 20 early-stage breast cancer survivors on Long Island, New York, I compared and contrasted women's coping strategies and methods of coping before breast cancer diagnosis and throughout the cancer continuum (i.e., at time of diagnosis, at time of staging, throughout treatment, and post-treatment). I also compared and contrasted women's communication patterns with their children before diagnosis, at the time of diagnosis and staging, throughout cancer treatment, and post-treatment. Two dominant themes emerged in this study: (a) the importance of relationships throughout the breast cancer continuum and (b) communication as a source of strength and resilience among survivors of early-stage breast cancer. Both themes provided a framework for understanding how mothers diagnosed with early-stage breast cancer coped and managed communication patterns with their children throughout the breast cancer experience.

This chapter includes an overview of the study, interpretation of the findings, discussion of themes, and implications for social change. Recommendations for practice, limitations of the study, and recommendations for future research precede my personal reflections and a conclusion.

Interpretation of the Findings

Part I: Coping Mechanisms

Research Question 1: What coping mechanisms did women use to manage their breast cancer diagnosis, stage of cancer, treatment, and aftermath of their cancer experience?

The findings are broadly in line with those of experts (Campbell-Enns & Woodgate, 2015; Eicher et al., 2015; Mazzotti et al., 2012; Molina et al., 2014; Sullivan-Singh et al., 2015) who have argued that emotional and social connections with other human beings is a requirement for coping and optimal psychosocial functioning among cancer patients. The findings generally supported my primary assumptions in this study, with evidence that cancer affects a mother's psychosocial functioning and ability to cope with cancer. Of importance in this study were categories and mechanisms of coping throughout the breast cancer continuum among mothers with early-stage breast cancer.

Coping Before Breast Cancer Diagnosis

I found that all respondents identified positive social connections and resources as fundamentally important in helping them manage psychological and emotional stress before diagnosis. Most identified a spouse, another close family member (a mother and/or sibling), and specific friend(s) who helped them through challenging times. Having had someone trustworthy with whom to talk during stressful situations and/or past traumas significantly helped participants recover from shock, grief, and loss. Participants in both G1 and G2 identified family and friends as providers of emotional comfort and support.

Participation in various meaningful social activities such as religion practices, spiritual practices, therapy, support groups, meditation, exercise, etc. significantly helped survivors work through difficult challenges and stressful life events. Engaging in meaningful activities with

family and friends provided a distraction and an outlet for detaching from the intensity of internal and external conflicts. These findings are consistent with previous research on relationships and coping (Tao et al., 2015).

I found that participants often remarked that having children provided a constructive outlet for reducing anxiety. Most thought that they became less entrenched in worry by focusing on the needs of their children. Despite the inherent responsibilities and stress that can accompany parenting, mothers created a proactive (problem-focused) approach to solving most problems. Survivors often thought that they needed to find their own ways to manage problems in order to help with their children's problems.

Initial Reactions to Breast Cancer Diagnosis

The diagnosis of breast cancer shook the foundations of each woman's life. Their descriptions of losing ground paralleled findings from Molina et al. (2014), and the confirmation of being diagnosed with a life-threatening illness dramatically challenged notions of certainty and security for each of them. Confirmation of breast cancer evoked thoughts of suffering and dying. Participants could not bear the thought of leaving their children, spouse, and loved ones. Once strong and resilient, participants briefly lapsed into despair as their lives caved in around them. They could not recall any prior experience that had left them feeling so helpless and without control over their lives.

Most women spoke openly and in depth about their grief over the anticipation of losing one or both breasts, and they unanimously experienced depression prior to surgical procedures. For all, the loss of a breast meant physical disfiguration as well as the loss of an integral part of their female identity. They saw their breasts as an important part of their physical attractiveness

and took pride in how their breasts complemented their body. The loss of breasts was linked with their perceived demise of their physical attractiveness.

The participants also associated their breasts with their maternal identities. All thought that having intact breasts validated their maternal function. These findings run counter to other studies (Mann et al., 2014). Of the participants in this study, 18 bonded with their children through breast feeding. The loss of breasts evoked profound loss for participants who recalled the intimacy of breast feeding. They deeply resented that they could no longer provide that same kind of bonding experience should they choose to have more offspring after remission.

Participants obsessed about how their breast cancer and treatment would affect their ability to care for their family. Those who thought their spouses and/or family members would have difficulty functioning without them possessed strong, dominant personalities. Those with more than one child focused especially on the youngest of their offspring.

Surprisingly, the women doubted that others would be able to care for their children in their absence. Lack of trust in their spouses, family members, and close friends to care for their children meant the children would not receive the *same* kind of care as that provided by their mothers. Logically, since approaches to care may differ from person to person, the women could no longer exert direct control over their children's care, which often evoked frustration and resentment toward those with more control.

At the time of diagnosis, as with coping mechanisms before diagnosis, survivors found that religion and/or spiritual beliefs helped rationalize their diagnosis. Additionally, religious and spiritual beliefs often helped participants manage physical and psychological challenges throughout treatment. Interestingly, despite moments of religious and spiritual disenchantment,

participants often associated early breast cancer detection and good/excellent prognosis to karma, the will of G-d(s), and/or the universe's and/or a higher power's plan for their lives.

Coping Mechanisms Used At the Time of Diagnosis

Although the survivors had multiple forms of emotional support prior to diagnosis, news of a life-threatening illness triggered immediate thoughts of their spouse and children. Despite efforts to emotionally prepare for the diagnosis, most were not able to avoid intense physical, psychological, and emotional reactions. Most had never experienced this kind of psychological, emotional, and physical stress before. In those first few moments after hearing the diagnosis, they remembered asking themselves, "How am I going to deal with this?" Most likened their experience to having their inner compass go haywire, as if they were losing ground.

Spouses, children, family, and close friends all played important roles in helping participants deal with the shock and grief of their diagnosis. I found that participants had mixed thoughts and emotions, both needing and wanting support and feeling that they needed to protect others from the nightmare of breast cancer. The survivors projected their narratives about breast cancer onto others; according to Mazzotti et al. (2012), such projection is not uncommon.

Participants found it highly beneficial to reach out to other women who shared a similar experience. Similar testimonies from peers allayed some of their fears. Weekly face-to face breast cancer support groups allowed for opportunities to share their thoughts and feelings. The use of the support group forum greatly increased participants' use of direct, open communication to help resolve conflicts at home, as well as with their medical teams.

Most women managed stage-related emotional duress by speaking with members of their medical teams and peers in their support groups. Medical teams, consisting of physicians, nurses, and social workers, helped participants manage the medical, psychological, emotional, and social

aspects of their breast cancer experience. When their medical team worked cohesively, participants felt secure and reassured that they had a powerful support system to help fight their breast cancer.

I found that survivors needed to believe in their medical team, particularly in their surgeons and oncologists. Outcomes of an effective patient-medical team relationship started at the time of diagnosis. Consistent open and direct communication with *every* member of the team helped participants come to terms with their diagnosis and manage their cancer treatment.

Regardless of participants' chosen support system(s), the breast cancer diagnosis affected the manner in which survivors managed stress. For most women, having to obtain emotional support through others outside the family system and/ network of friends was challenging. The breast cancer experience appeared to have evoked a sense of urgency among the survivors. Women felt vulnerable sharing their profound personal experiences with strangers. Women also recognized the need to be with others, particularly with those who had similar experiences. All needed to know that others were facing the same kind of hell.

Most were inspired to go beyond the comfort of what was familiar to them. Several participants remarked on how they would never have imagined themselves relying on others to cope. The women were more focused on helping other women and less focused on their own needs. An important feature of breast cancer support groups was that they allowed for reciprocity, where women could give and receive support to each other.

Initial Reactions to Breast Cancer Stage

Surprisingly, the sample did not choose to focus their attention on either cancer stage or its impact on their motivation for recovery. Most, overwhelmed by the diagnosis in and of itself, chose to manage thoughts and feelings about stage by categorizing it as mainly useful to the

medical team in determining treatment protocols. Participants understood their stage as a marker for knowing the extent of breast cancer. Knowledge about stage reminded participants that they *could* have been diagnosed at a later stage. Most felt their stage was a constant reminder of how lucky they were to have been diagnosed at an earlier stage.

Coping Mechanisms Used at the Time of Breast Cancer Staging

I found that most G1and G2 participants accepted their stage of cancer, but chose to relegate the information to their medical teams to help determine the course of treatment. The findings also suggest that G1and G2 participants choose not emphasize breast cancer stage, based on the recommendation from their oncologists to avoid assumptions about outcomes and prognosis. Women most often turned to members of their medical teams to address technical concerns about staging. Most found security from the medical team's expertise of cancer stage. Some were reassured by the clinical knowledge of their medical teams, but G1and G2 participants also bonded with some team members and attained an emotional connection, which helped allay staging concerns.

Participants from G1and G2 also used their breast cancer support groups to express anxiety and/or other emotional stress related to breast cancer stage. The support groups provided much-needed solidarity among breast cancer survivors. G1and G2 participants found validation of their fears and concerns, as well as a supportive and constructive outlet to discuss strategies for managing the impact of staging on attitude and outlook.

To manage cancer stage-related stress, most women refocused their attention on treatment, recovery (remission), and parenting. Most mothers moved away from thinking of their stage as a final outcome and determination for survival; rather, they chose to concentrate on getting through treatment, getting better, and optimally resuming their lives. Most identified

motherhood as a dominant factor for regulating thoughts and feelings about stage. Using an emotion- and problem-focused approach to coping, women thought that *regardless* of stage, their only choice was to conquer the cancer because their children needed them.

Most survivors thought that the initial diagnosis and preliminary staging prepared them for post-surgical stage confirmation. Although anticipating the pathology findings after surgery was highly stressful, most used their support groups as an outlet for processing fears and concerns related to stage. All participants primarily focused on treatment-related concerns over staging. Those diagnosed with stage IB and IIA/B breast cancer focused on preparation for the *possibility* of a more advanced stage than previously thought by the surgeon/medical team.

Those diagnosed with stage IB and IIA/B breast cancer appeared more guarded and anxious about their stage. Regardless of stage, G1and G2 participants alike could not exert control in their lives in the manner they once did. They felt forced into accepting limitations like never before. For most, not having full control was a valuable lesson, creating a narrative of letting go and trusting in their ability to physically, psychologically, and emotionally cope with their breast cancer experience. Several used the time of staging to master the skills necessary to manage their breast cancer treatment.

Coping Mechanisms Used Throughout Treatment

While participants dreaded the thought of radiation therapy, chemotherapy evoked images of suffering and death. Most feared chemotherapy more than the breast cancer itself. They could not reconcile the poisonous effects of the treatment with destroying their cancer. Participants surrendered to the conviction that the hell of treatment, with all its suffering, was their only hope of survival. The experience of letting go and allowing time for the benefits of treatment to appear helped the women cope throughout treatment.

The importance of maintaining parental identity throughout treatment cannot be underestimated. Participants desired to be included in parenting while in treatment. Others' assumptions about their physical and psychological limitations evoked resentment among participants. A majority of the participants recalled many spousal and family conflicts over assumptions about whether they had the capacity to care for children while in treatment. Participants did not want assumptions made about them, especially when it came to their children. While in treatment, they expected to be asked openly and directly about *their* ability to parent. Participants would have appreciated an understanding that motherhood does not cease during the cancer continuum.

Cancer treatment appeared to have had both deleterious and valuable impacts on how the survivors interacted with their children and others. Importantly, the maternal role motivated participants to better manage the physical, psychological, and emotional impacts of treatment. Furthermore, the duration of treatment provided participants with time to reflect. Participants felt forced into facing inner silence. Reflection inspired a determination to become more patient with their circumstances. Surprisingly, most participants thought the opportunity helped them to achieve self-acceptance and the ability to be more patient, given the degree of physical discomfort and psychological malaise caused by treatment.

Most participants found comfort throughout treatment when interacting with their children. Marly Girl (G2) was the exception to the rule. She spoke of wanting to be left alone much of her time in treatment and resented having to go through cancer treatment. The effects of radiation and chemotherapy rendered her physically, psychologically, and emotionally depleted. Contributing to her misery were thoughts of uselessness and powerlessness. Marly Girl spent most of her days in isolation and could not find solace through parenting.

The short-term and long-term effects of treatment, such as neuropathy, loss of memory, poor concentration, balance issues, etc., prevented most women in G2 from resuming some physical activities. These women recalled having to limit many recreational activities for months after treatment. Several had to limit social involvement due to the physical and neurological effects of chemotherapy. All of the women often experienced social anxiety and were preoccupied with the judgments and perceptions of others.

The women lamented the debilitating effects of treatment which kept them from being fully present to the needs of their children. While side effects affected their interactions with people within and outside the family system, the women often used these limitations as teachable and learning moments. Limitations became a springboard for most to embrace and accept the consequences of cancer treatment. Women used their treatment time to reflect on purpose and meaning, reevaluate relationships, and focus on goals that were once thought of as impossible.

Coping Mechanisms Used Post-Treatment into Survivorship

After being diagnosed with early-stage breast cancer, completing cancer treatment, and going into remission, participants experienced an initial euphoria associated with survivorship. They felt reborn despite the loss of breasts and the residual effects of treatment. Given their second chance, most felt obligated to support other survivors. There appeared to be a collective responsibility felt among participants to share their breast cancer experience with others. Some may have felt pressured by fellow survivors or cancer center staff to use their experience as a tool for advocacy.

To manage the uncertainties of recurrence, all created narratives from their survival of breast cancer. A primary understanding was a personal obligation to appreciate life and to honor the strength that had helped them endure the treatment process. The cancer experience helped

them to accept uncertainty with greater ease. De-emphasizing a need to figure everything out and accepting realistic limitations appeared to be a factor in promoting physical, psychological, and emotional strength.

Most participants in G2 worried about recurrence regardless of family history and/or confirmation of BRCA gene mutation. Two women in G1 shared similar concerns of recurrence. One participant received confirmation through genetic testing that she carried the BRCA 1 mutation. I found that women diagnosed at later stages of I/II exhibited the most anxiety about recurrence.

Women with stage IB were closer to stage IIA/B, those with stage IIA were closer to IIB, and IIB closer to the beginning of a later stage (III). The closer a women's stage was to a later stage, the more anxiety she had about the possibility of recurrence. The shared primary concerns were (a) having to undergo more cancer treatment and (b) the impact of recurrence on children. Most women in G1 appeared to have resolved concerns of recurrence, or perhaps chose not to focus on recurrence as a coping defense.

More than half of the participants credited their children's positive coping skills and resiliency with their own better management of anxiety and depression associated with health uncertainty.

Remarkably, children's strength and resilience throughout the cancer experience inspired participants to appreciate their maternal role, while aspiring to be better mothers. The identification of what it means to be a better mom began when participants recognized that they already possessed the characteristics and traits of a good mom.

The breast cancer experience allowed for time to gain greater insights into how they defined motherhood and portrayed their parental role. All recognized greater awareness of the

emotional bonds with their children. Other benefits included a deeper appreciation of interactions with their children and increased patience with their behaviorally challenged children.

Survivors were inspired to accept the now and live in the present moment. Participants learned how to value and integrate more self-care practices without guilt. Having lived with a serious illness, they realized that life is unpredictable and can be shortened by circumstances beyond our control.

Participants no longer settled for wasting time and used both old and new coping skills to confront fears and concerns about the uncertainties of breast cancer (i.e., recurrence). Barring the death of a daughter and/or son, participants thought that they could survive anything after having breast cancer. Participants used the physical, psychological, and emotional duress associated with early-stage breast cancer to empower their determination to survive.

Part II: Communication Patterns

Research Question 2. Did communication between mothers and their children change because of their breast cancer diagnosis?

The findings supported the primary assumptions of this study with evidence from previous studies (Al-Zaben et al., 2014; Batenburg & Das, 2014; Campbell-Enns, & Woodgate, 2015; Donovan-Kicken et al., 2012; Mazzotti et al., 2012; NCI, 2015a), specifically, the assumption that effective communication is an important component in the overall psychosocial health of cancer patients. The emotional impact of cancer informs the way in which cancer patients manage communication patterns with others. Of importance to this study were communication patterns between mothers and their children throughout the cancer continuum.

Differing from previous studies, my methodology included communication styles *and* communication patterns between early-stage breast cancer survivors and their children in five

time periods (before diagnosis, at time of diagnosis, at time of staging, throughout treatment, and post-treatment). I examined how breast cancer impacted communication between mothers and their children throughout the cancer continuum. The findings confirmed that communication patterns changed because of breast cancer diagnosis and staging. Communication patterns, which were regulated by a mother's emotional reaction(s), related to adaption to diagnosis, stage, treatment, and post-treatment survivorship.

Primary Communication Patterns Before Diagnosis

Most of the participants did not consider communication styles and/or patterns with their children before diagnosis. However, participants found communication to be a principal factor for effective parenting. Interview questions prompted recollections of their preferred methods of communication while interacting with their children. Participants described specific modes of communication.

I categorized style(s) of communication based on those accounts. Interestingly, Lagerdahl et al. (2014) found that mothers used patterns of communication without awareness as to why they preferred one mode over another. In this study, I found that participants correlated their use and methods of communication with influences of the primary family system, or family of origin.

More than half of the survivors credited their personality traits and personal experiences for their understanding of communication and its use in social situations. Both McMaster's theory of family functioning, as well as Batenburg and Das (2014), made similar assertions in their studies. I found that the individual personalities of the children and the nature of mother-child bonds affected communication with their children, as Mazzotti et al. (2012) concluded in their research.

The participants adapted pre-existing styles of communication to the practical needs of their children and/or nuclear family system. Primary and preferred methods of communication before diagnosis included combinations of direct, open, and indirect communication. Secondary styles of communication involved use of direct, open, and third-party communication. They used open, direct, and indirect communication to convey information for meaningful and practical purposes. Direct and indirect verbal interactions included face-to-face contact, telephone calls, and, in some instances, SKYPE. Direct, non-verbal communication included text messages, emails, and written notes.

Participants often used third parties - spouse, children, and other family members - to disseminate information. Participants used communication to engage their children through instruction and task completion. The sole function of communication was to reinforce important matters of daily living. When communicating with their child, participants considered their child's developmental stage and temperament.

Prior to diagnosis and treatment, the women saw themselves as gatekeepers of the family and the home. A primary function of this maternal identity included gathering, interpreting, and articulating crucial and practical information. Furthermore, participants used communication to teach, nurture, and ensure their children's overall well-being.

A majority of participants used communication to inspire greater confidence and independence among their children. I confirmed two important propositions from McMaster's understanding of the maternal role within family systems, as well as claims made by Molina et al. (2014): (a) communication is the cornerstone of family structure and organization and (b) mothers play an integral role by maintaining family structure through managed communication.

The sample used a variety of techniques to communicate with their children. Although direct, face-to-face, verbal interactions provided participants with the most satisfaction, non-verbal messages or indirect communication (body language, notes, emails, text messages, and voicemail) sufficed to relay intimate feelings. Lagerdahl et al. (2014) reported that mothers use communication to reinforce closeness, while reassuring children that they can confide in their mothers and rely on them for emotional security. Similarly, survivors wanted their children to develop secure attachments in order to strengthen relationships and ensure a positive approach to parenting. Interestingly, they retrospectively assessed whether their communication methods were effective and helpful to their children before diagnosis. Most participants thought they did the best they could.

Primary Communication Patterns at the Time of Diagnosis

The emotional impact of a breast cancer diagnosis contributed greatly to how the women chose to share the news with their children. Following the initial shock of diagnosis, participants needed time to come to terms with the harsh realities of their fate. The realization of the illness left participants speechless. In contrast to the findings of Al-Zaben et al. (2014), an overwhelming majority requested the company of a supportive third party when it came time to tell the children. Third-party choices included individuals with close ties to both the participants and children. In addition to a spouse, some participants chose a parent, (usually their mother), sibling, or close friend for additional support.

Franny (G1) did not experience the emotional intensity experienced by most in both groups at time of diagnosis. She recalled having brief break-down moments, but felt the need to talk about her initial diagnosis with others. Franny thought that it was important to inform her children of the diagnosis. She revealed her diagnosis by using an age-appropriate approach

suggested by the social worker at the Cancer Center. Franny thought it was important to speak about her diagnosis openly.

Primary Communication Patterns at the Time of Staging

Franny (G1) was the only one who did not withhold communication about breast cancer stage from her children, loved ones, and friends. She was much less inhibited by her stage (stage 0) because it was not as threatening as the later stages. Cherrylady (G2) often felt consumed by her stage (IIA) and needed to discuss her thoughts and concerns within and outside of her support group. She chose not to disclose information about stage to her daughter. Cherrylady thought cancer stage would confuse her daughter and present unnecessary concern.

Communications about cancer stage were reserved for the medical teams and/or breast cancer support groups. Aside from not sharing knowledge about their cancer stage, the women did not alter communication styles and/or patterns with their children at the time of staging. Most avoided having to discuss cancer stage with their children and thought revealing cancer stage was unnecessary. Of the few children who inquired about their mother's stage, mothers redirected them to the purpose and function of the staging system as put forth by their medical teams. Participants in G1and G2 reiterated to their children that stage does *not* determine exactness of life expectancy.

Primary Communication Patterns Throughout Treatment

Throughout treatment, participants experienced side effects from radiation therapy, chemotherapy, and hormone therapy. Side effects resulted in physical, psychological, and emotional challenges. Breast cancer treatments often rendered participants weak and, at times, unable to function. Treatments made communication with their children difficult, as mothers experienced extreme fatigue, stomach sickness, and irritability.

The women often found it difficult and, at times, nearly impossible to use direct and open communication while undergoing treatment. As noted in Mazzotti et al. (2012), mothers often used third-party and indirect communication with their children throughout treatment. As time passed, it became increasingly difficult for mothers to think of themselves as effective parents. Paradoxically, mothers needed the treatments to eradicate the cancer, but those same treatments limited communication and bonding.

Throughout the duration of breast cancer treatment, participants spent much of their time alone. They used this time for profound soul-searching. Despite moments of hopelessness and despair, they felt forced to face inner demons and take inventory of their lives. The women chose to focus on what they had control over by attaching to the present moment. By remaining conscious of the moment, they were fully present to their physical, psychological, and emotional experiences.

Although verbal communication had been limited by the side effects of treatment, they used online and paper journals/diaries to express thoughts, feelings, fears, and hopes through words, symbols, pictures, and drawings. Interestingly, some participants asked their children to contribute writings, pictures, and other material to make it a joint effort. The journal/diary provided mothers with a creative medium with which to bond with their children.

While undergoing breast cancer treatment, women experienced a profound physical, psychological, and emotional detachment from their children. They resented the time they lost with their children. This absence or lack of mother-child bonding evoked an awareness among participants that initiated a positive, proactive change in communication between mother and child. Since having breast cancer, the survivors found that they wanted to spend more quality

time with their children. This quality time included a process of re-acquaintance. Mothers noticed more of an attunement to their child's verbal and non-verbal communication styles.

Post-Treatment and Survivorship Communication Patterns

Inspired by their experience of profound isolation and alienation during cancer treatment, mothers recognized the value of consistent, direct, and open communication. The breast cancer experience accentuated the emotional dimension of communication between participants and their children. As in Sullivan-Singh et al. (2015), influenced by the possibility of a shortened lifespan, survivors no longer viewed communication as just a practical way of instructing or relaying valuable information. Communication became synonymous with the value of time, which they could no longer take for granted. They used communication as an intentional source of mental and emotional cohesion to bond with their children.

Part III: Comparison of Themes

Relationships as a Mediating Factor for Coping

Of all their relationships, both groups showed a clear preference for an emotional connection with their children. The mother-bond relationship emerged consistently throughout the cancer continuum as the dominant relationship. However, mothers also valued their relationships with their spouses and/or others. It should also be noted that a lack of data prevents us from determining whether mothers bonded more with one or more offspring than with others.

The survivors shared more similarities than differences in their coping mechanisms before their breast cancer diagnosis, at the time of diagnosis, at time of staging, throughout treatment, and post-treatment or remission (see Appendix A). A dominant theme of coping with stress was associated with significant, meaningful relationships. They identified spouses, children, close family, and friends as primary sources of managing stress. Meaningful activities,

whether alone or with loved ones and friends, helped manage anxiety and enhanced well-being. Thirty percent of G1 women and 50% of G2 women emphasized that caring for their children was an effective way of dealing with stress.

At the time of diagnosis, most thought that their primary support came from three sources: (a) their spouse, (b) their children, and (c) their medical teams. Participants in G2 were more candid about emotional support, specifically from social workers at the breast center. The participants from both groups remarked on the importance of the nurses on their medical teams for medical knowledge, understanding, and emotional support. In G2, 60% of participants thought the social worker was extremely helpful linking them to resources, especially for their children and spouses.

At time of staging, the survivors managed stage-related anxiety by reaching out to members on their medical teams and/or through discussions in their support groups. Most experienced an elevated level of anxiety between their initial surgical procedure and the confirmation of staging. In most cases, pathology reports were not available for up to three weeks, given the arduous nature of determining and confirming stage. Throughout the waiting period, the women used their support groups and individual counseling sessions to cope with the uncertainty.

Half of the women in G1 and all of the women in G2 required more intensive rounds of radiation and chemotherapy. This treatment, based on their specific stage, often included a longer time frame. Within a few weeks of chemotherapy, 50% of G1 and 90% of G2 participants came to the realization that surrendering to the process of chemotherapy would benefit them. These same women thought that not resisting the physical effects of treatment might help ease the psychological and emotional stress of treatment. With the exception Cherrylady (G2), survivors

found that their parental role was a healthy and welcomed distraction throughout treatment. Focusing on the needs of their children often helped women to manage the deleterious impact of cancer treatment.

Months following their last cancer treatment, survivors believed that the experience had opened their eyes, minds, and hearts to life. Most thought that they had a responsibility to take better care of themselves and to help others facing breast cancer. They were grateful for surviving breast cancer. They had grappled with profound illness and the possibility of death but had learned to master adversity. Most spoke of now being able to embrace uncertainty with acceptance and peace. All agreed that motherhood was a key factor in helping them cope with the cancer experience. Ma-Tree summed up both groups' sentiments:

> We talked in group all the time about how our kids drive us crazy and how we want to kick them in the butt from time to time, but they (children) got me out of the bed and will always be an important part of what keeps me going, gratefully going along (laughs with tears in her eyes).

Communication as a Source of Emotional Strength and Survival

Both groups shared similar communication patterns before diagnosis, at time of diagnosis, at time of staging, throughout treatment, and post-treatment (see Appendix B). Everyday use of verbal and non-verbal expression emerged as a primary source of survival and was a widely noticeable theme for communication patterns. Before diagnosis, participants recalled having a limited understanding and use of communication with their children. For most of the survivors, communication before diagnosis was taken for granted and used for instruction. Several recollected about how they often used communication to relay emotion and show affection toward their children by way of hugs, kisses, hand holding, etc.

Most women found that the intense emotional impact of diagnosis initially affected their ability to interact with their children. At the time of diagnosis, the women recalled feeling sad and grief-stricken whenever they would see their children's faces or hear their voices. Several women in both groups remembered wondering if they would die before their children became adults. The survivors wanted to protect their children from the impending nightmare of breast cancer. Most found it difficult to avoid their children and wanted to tell their children about the diagnosis. With support from spouses, family members, and their medical teams, children were told of the diagnosis in a sensitive, age-appropriate manner.

Most in participants in G1 and all in G2 withheld discussions about staging from anyone other than a member of their medical team or other breast cancer survivors. The survivors found the staging process confusing and would therefore not expect others to understand. Most understood staging to be a part of the overall diagnosis, but knowing that they had a diagnosis of cancer was initially more important to them. They relied on their oncologists and nurses to address concerns pertaining to the medical aspects of staging. Their medical teams reassured the women that stage helped determine the course of treatment and should not be used as an absolute marker for prognosis.

Both groups determined their communication patterns throughout treatment. Most participants in G1 did not undergo the kind of intense and prolonged treatment faced by those in G2. In G1, 70% of women completed treatment and recovered sooner than all of those in G2. On average, most of the G1 participants reported feeling better in less time than those in G2. In G1, 40% of participants recalled being able to communicate regularly with their children throughout treatment. Sixty percent of G2 participants recalled that interaction with their children did not occur on a regular basis because of the physical and psychological effects of chemotherapy. All

of the participants concurred that many interactions with their children throughout treatment helped them to manage treatment's side effects. Trumom (G1) captured the essence with her response:

> My kids were a blessing, great distraction, whatever, it worked! (giggled with tears in her eyes). My daughters kept me sane and as loveable as anyone could be with poison floatin' around in their guts and veins.

Following their final treatment, survivors found interactions with their children more enjoyable. Several women in G2 commented that time spent with even the most challenging child had improved. All spoke of spending more time listening to their children and less time focused on the superficiality of daily life.

In G1, 70% of participants thought their breast cancer experience helped improve communication with their children. In G2, 80% of participants recognized a favorable change in communication between them and their children. All attributed positive changes in communication to (a) their children's empathy regarding their mother's suffering, (b) emotional and physical detachment between mother-child at times throughout the cancer experience, (c) greater awareness of mortality and limited time, and (d) deeper appreciation for the mother-child relationship.

Part IV: Woman to Woman: Advice to Other Breast Cancer Survivors

Advice that emerged from early-stage breast cancer survivors to other women facing early-stage breast cancer included (a) knowing family history and genetics, (b) seeking peer support, (c) maintaining parental identity throughout all phases of the breast cancer continuum, (d) advocating for self, and (e) encouraging support groups for children.

Knowledge of Family History and Genetics

As part of their personal and collective mission of advocacy and empowerment, the participants unanimously thought that women should know whether they had a family history of cancer, especially breast cancer. Knowing family history provided participants with options to considerably lower their risk and prevent future cancer. Although genetic screening for breast cancer and/or other cancers (BRCA1 and BRCA2) provided knowledge about genetic predisposition, it did not reduce the stress related to diagnosis or treatment. Knowing their family history and BRCA status would later help determine the cancer risk for their children. Paradoxically, this information exacerbated mothers' anxiety and evoked worry. The greatest benefit of knowing their BRCA status was to help the women and their oncologists make better informed medical decisions.

Survivors overwhelmingly advocated for breast cancer survivors to participate in a weekly face-to-face support group. Some felt it best to be in a group specifically related to cancer stage. Most proposed a specialized group just for mothers with early-stage breast cancer. Both suggestions made a considerable amount of sense, given participants' needs. Although identified as early-stage breast cancer, stage IIA/B is more advanced than stage 0, IA/B. Therefore, those women tended to feel more anxious and concerned about advancing to a later stage.

Supportive Solidarity

Another important group forum requested by participants was a weekly group to discuss parenting concerns. Parents with cancer, specifically mothers with breast cancer, have different psychosocial needs than those without children or those with adult children. Participants often felt uncomfortable bringing up parenting issues to their support groups out of concern for women

without children and/or older women with grown children. Participants did not want to overwhelm their groups with mother-child concerns. Despite the support and feedback from group participants about parenting concerns, participants acknowledged that they would have felt more comfortable in a group specifically designed for their needs, such as one exploring how mothers maintain their parental identity throughout all phases of breast cancer.

Cancer or No Cancer, We are Still Moms

The participants acknowledged that a diagnosis of breast cancer and/or cancer treatment should not exclude them from being active parental figures. However, as part of effective, open, and direct, communication, women also needed to engage spouses and family members in a post-diagnosis, pre-treatment discussion about their expectations and assumptions. Active parenting throughout the cancer continuum clearly helped participants manage anxiety and depression. Participants did not explore concerns about parenting while undergoing treatment prior to the start of treatment because they did not know what to expect. In hindsight, they would have communicated how they wanted to maintain their parental role based on how they felt on a moment-to-moment, day-to-day plan.

Empowerment of Self

From their own experiences, the women recommended that mothers diagnosed with breast cancer learn to set boundaries. Self-advocacy emerged from the realization that participants needed to focus more on self-care principles. They had difficulty letting others care for them because it threatened whatever autonomy they had, especially throughout treatment. They had to face their control issues and let their guards down, yet still remind others, especially their children, that sick or not sick, they remained in charge. Surprisingly, only one participant

knew of the Women's Health and Cancer Rights Act (WHCRA) of 1998. WHCRA is a federal law providing legal protections to patients with breast cancer.

Empower Your Children with Tools to Cope with Mom's Cancer

Initially, participants felt indifferent toward the idea of a support group for their children. Participants thought that their children would not be interested in or benefit from a support group. A social worker from the cancer center challenged their assumptions by asking them not to make the same mistake they claimed others did by making decisions without exploring it with their children. Most accepted the social worker's challenge and found that their children wanted to participate. Participants signed their children up for an eight-week support group, divided according to age. Participants reported that those who participated in a weekly or bi-weekly support group demonstrated significant improvements in physical and mental health, resulting in fewer absences from school.

Implications for Social Change

Breast cancer effects women of all socioeconomic, ethnic, and racial backgrounds. The findings of this study decrease disparities in women's health care by drawing attention to the universal psychosocial health care needs of women diagnosed with early stage breast cancer around the world. This paradigm can be used as a model to help mothers and their children cope with the different phases of breast cancer (e.g., at the time of diagnosis, throughout treatment, and post-treatment). Through oncological human service systems, mothers can access and apply coping-communication skills to their individual breast cancer experience. The model of coping-communication presented in this study may be adapted to cultural norms.

Based on the parameters and findings of this study, I presented a broader social awareness of specific psychosocial needs among early-stage breast cancer survivors. The

findings included that the mother-child relationship is a mediating factor for managing psychological and emotional stress throughout the breast cancer experience. This relationship, supported by effective communication, resulted in successful coping skills for both mothers and their children. This interplay between mothers and their children goes beyond the boundaries of individuals and family systems. Oncology teams could use the data to create or enhance policy and protocols for health professionals in various settings in which cancer patients and their family members access services (e.g., hospitals, outpatient clinics, and community-based mental health services).

Recommendations for Practice

Best Practice Initiatives

Knowledge gleaned from the lived experiences of early-stage breast cancer survivors can be useful in enhancing the current methods of service delivery in various clinical settings. As a result of these findings, oncology healthcare professionals can implement practice strategies to address (a) barriers to effective communication between breast cancer patients and their loved ones, (b) coping strategies at the time of initial diagnosis throughout treatment, remission, and transition to survivorship, and (c) implementation of maternal health and wellness interventions with an emphasis on the psychosocial needs of mothers diagnosed with early-stage breast cancer.

Using the strengths perspective, options for a comprehensive practice model would include a patient-centered approach as women came to terms with a confirmed diagnosis of breast cancer. Clinicians can help patients process their initial reactions to the diagnosis. Pre-existing and current coping mechanisms might also be evaluated as patients come to terms with a chronic, life-threatening illness. The primary focus of intervention should be on the diagnosis

itself and not on breast cancer stage. The evaluative process might also involve a discussion about the positive aspects of support groups for patients and their children.

In their initial assessments and therapeutic goal planning with breast cancer patients, clinicians can include a discussion and evaluation of pre-existing and current communication patterns. Communication shapes human interactions and is important for optimal psychosocial functioning; however, ironically, the awareness and understanding of communication styles and patterns is often overlooked. The breast cancer experience affects communication patterns between breast cancer survivors and their children. Communication can be halted, thus negatively impacting the mother-child relationship. With psychosocial guidance, patients can learn to use effective communication throughout the cancer continuum to develop and maintain emotional bonds with their children and others.

Effective communication also aids in coping with cancer-related psychosocial stress. To manage the physical, psychological, emotional, and social impacts of cancer treatment, patients can use the mother-child bond to reinforce parental identity. Allowing for active participation in parenting throughout the cancer continuum benefits the child, as well as the mother. Furthermore, as part of a parenting strategy, clinicians can encourage patients to incorporate creative elements into their communication patterns with children. By using written journals, drawings, photos, and video and audio recordings, patients and their children can bond through the sharing and exchanging of ideas, thoughts, and feelings about the breast cancer experience.

Limitations of the Study

This study involved a retrospective process that invoked mothers' memories about (a) their initial reaction(s) to the diagnosis, (b) changes in communication patterns with their children, and (c) coping mechanisms used throughout the breast cancer continuum. Participants

often exhibited limited recollections of events and interactions with their children. To manage these limitations, I created a context and provided additional time for participants to recollect memories of the emotional and psychological impact of early-stage breast cancer.

More than half of the sample developed an idealization of breast cancer survivorship one year after of their diagnosis, treatment, and recovery. Participants often experienced mild states of emotional euphoria from their recovery experiences and anticipated remission. Although diagnosed with a more advanced stage of breast cancer, G2 participants understood that their prognosis was as good and advantageous as those of G1 participants. Women in the sample often remarked on how their prognosis may have helped shape a slightly more positive perception of their experience.

The sample included women from diverse ethnic backgrounds (African-American, South Asian, East Slavic, West Indian, Euro-American, and European). Ethnic composition limited my ability to broaden the scope of experiences belonging to breast cancer survivors within other groups. More than half of the survivors included African-American and Euro-American women. The sample under represented women from South Asian, East Slavic, West Indian, and European backgrounds. Although infrequent, cultural boundaries limited full disclosure. Two of the women who identified as Muslim gave one word responses (yes or no) when asked about deeply personal accounts of their experience, such as fear of spousal rejection after mastectomy.

Recommendations for Further Research

Expectedly, the boundaries of this study did not allow for an in-depth examination and analysis of inquiries that emerged from the data. These included (a) the influence of family, personality type, and personal experiences on communication and coping, (b) the impact of breast cancer on communication patterns and coping for the children and spouses of breast

cancer survivors, (c) the meaning and use of time among early-stage breast cancer survivors (socio-emotional selectivity), and (d) the emotional, psychosocial, and ethical implications of genetic testing. Further studies may provide researchers and oncology professionals with insights about improving psychosocial functioning among early-stage breast cancer patients/survivors.

As such, new data generated from future investigations can append the body of knowledge in the disciplines of medical and psychosocial oncology. Examining how breast cancer survivors use internal and external resources may broaden the scope of knowledge for oncology professionals seeking to improve the quality of psychological, emotional, and social functioning among breast cancer patients/survivors and their loved ones. Considerations for future research studies include:

1. How do family background, personality type, and life experiences shape communication patterns and coping mechanisms among breast cancer survivors? By developing a conceptualization of the interplay between these factors, oncology professionals can develop psychosocial interventions to (a) create and enhance communication patterns between early-stage breast cancer survivors and others and (b) improve maladaptive coping skills among early-stage breast cancer survivors.
2. How do spouses and/or children of breast cancer survivors manage communication patterns and coping throughout diagnosis, treatment, and post-treatment? What advice do they have for other spouses and children of early-stage breast cancer survivors?
3. How does socio-emotional selectivity impact communication and coping mechanisms among breast cancer survivors? In this study, participants thought early-stage breast cancer (0-IIB) changed their perspective about time. Breast cancer diagnosis, treatment, and post-treatment impacted how mothers defined and used time.

Participants found themselves being more appreciative of time and demanding more quality time with loved ones after realizing the possibility of a shortened life span. A comparison of socio-emotional selectivity between early-stage breast cancer survivors (0, – IIB) and those diagnosed with a later stage of breast cancer (IIIA-IIIC) may help researchers and oncology professionals better understand how breast cancer survivors use socio-emotional selectivity to manage communication patterns and coping with uncertainty.

4. Psychosocial challenges experienced by early stage breast cancer survivors may apply equally to mothers with other types of cancers not explored in this study.
5. What are the emotional and psychosocial implications of the BRCA gene test for breast cancer survivors and their children? Most participants in this study opted for genetic testing. Of the six participants who tested positive for the BRCA1or 2 mutations, four felt emotionally conflicted about telling their children. Their children have a 50% chance of carrying the mutation. It is unclear among researchers and professionals when children should be told about their mother's status or at what age testing should start. While having knowledge about BRCA can help breast cancer survivors make better informed healthcare decisions, there is limited data regarding the psychological, emotional, social, and ethical ramifications of BRCA testing for the children of breast cancer survivors.

Researcher Reflections

I went into each interview with assumptions and pre-suppositions based on my family history, my years as an oncology social worker, and data from various studies. I knew it would be emotionally draining for me. When I was just 16, my mother died at age 41 from

complications of late-stage breast cancer. When I was 46, my youngest sister survived early-stage breast cancer. By the second or third interview, I realized that the questions I had about my mother's breast cancer experience were answerable through my research. I had wondered for many years why she lived longer than the doctors expected. I see now that her survival and coping skills could have been affected by my bond with her. After her death, my father confided in me that *he* believed she lived as long as she did because of a determination to care for me and my three siblings.

Every mother I interviewed moved me emotionally by their recollections of suffering, loss, and recovery. I was inspired by the mothers' use of their children's strengths and resilience as a way to cope with breast cancer treatment. I found most of the mothers to be positive and forthright. The humor and joy amidst tears of sorrow made the interview process even more real and authentic. Mothers wanted to be viewed as helpful and often stopped and asked if they answered correctly or if I needed more elaboration from them. I came to deeply admire every participant for their wisdom, insight, courage, and strength. Through these wonderful women and mothers, I embraced a new understanding and appreciation for my mother's breast cancer experience.

I was surprised to learn early on that surgeons and oncologists discouraged women from focusing on their stage of breast cancer. An oncology nurse explained that women often used stage as the sole measure for prognosis and either become overly complacent if diagnosed an early stage or highly anxious if diagnosed at stage IB or later. One participant told me that some women in her support group turned staging into a competition, explaining that some group members would compare their stages with others and viewed stage of breast cancer as a badge of honor for their strength and/or reminder of how they had escaped a later stage.

BRCA1-2 gene testing appeared to be important for some participants. I wondered why it was that some women opted out of having themselves tested. Perhaps it was avoidance? I was surprised and emotionally moved by how many women used their children's psychological and emotional strength to help them cope with the cancer experience. Women appeared to have cared for themselves through their children; they did not *define* who they were through the title or function of motherhood but rather within their *relationship* with their offspring.

Conclusion

The purpose of this study was to examine the complexities of the relationship between early breast cancer staging, mother-child communication processes, and coping strategies of mothers with early-stage breast cancer. I compared and contrasted mothers' understandings of how breast cancer affected their (a) thoughts and emotions, (b) ability to parent, (c) modes of communication with their children, and (d) coping mechanisms used to manage the uncertainties of early-stage breast cancer. Early-stage breast cancer shaped communication patterns between mothers and their children. Mothers used various coping mechanisms to manage psychological stress at the time of diagnosis, throughout treatment, and following treatment.

Family background, personality, and firsthand experiences may have shaped communication styles of mothers, but the subjective nature of the mother-child relationship appeared to determine the method and quality of communication between them. Regardless of whether coping skills can be attributed to upbringing, personality, or a history of traumatic events, mothers found their role as parent to be a source of comfort and strength. Throughout the breast cancer experience, mothers viewed the mother-child relationship to be an integral part of managing the deleterious effects of breast cancer. Maternal use of effective, direct, and open communication with their children throughout the cancer experience helped foster a stronger

bond between them. Mothers coped better with breast cancer when they maintained their parental identity. Although different for each woman and not analogous to their personhood, women used their motherhood and parental identity as a motivation for survivorship. In her personal journal, *Through Mama's Eyes: Surviving Breast Cancer,* ProudMama (G2) wrote:

> I think recording artist and activist, Melissa Etheridge, was on to something when she said, cancer was an opportunity to sit down and look inward to find the answers. I believe with all my heart that being a mom emboldened me to fight even harder. How ironic is it that I gave my daughter life and our bond inspired me to live and to thrive within uncertainty.

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Appendix A: Comparison of G1-G2 Coping Methods

G1 Time Period	G1 Coping Method	G1 Response Count
Coping Before Diagnosis	Family/Friends	10
Coping at Time of Diagnosis	Family/Friends Medical Team	7 3
Coping at Time of Staging	Medical Team/Support Group Family/Friends/Medical Team Family/Friends	6 3 1
Coping Throughout Treatment	Family/Friends/Medical Team Family/Friends Medical Team/Support Group	5 3 2
Post Treatment Coping	Medical Team/Support Group Family/Friends/Medical Team Family/Friends	4 3 3
G2 Time Period	**G2 Coping Method**	**G2 Response Count**
Coping Before Diagnosis	Family/Friends	10
Coping at Time of Diagnosis	Family/Friends Medical Team	6 4
Coping at Time of Staging	Medical Team/Support Group Family/Friends	8 2
Coping Throughout Treatment	Family/Friends/Medical Team Family/Friends	6 4
Post Treatment Coping	Friends/Family/Medical Team Medical Team/Support Group	5 5

Note. n = 10 in each group.

Appendix B: Comparison of G1-G2 Communication Patterns Between Mother-Child

G1 Time Period of Communication	G1 Communication Pattern(s)	G1 Response Frequency
Communication Before Diagnosis	Direct/Open/Indirect Direct/Open/Third Party Third Party/Avoidant	5 4 1

Communication at Time of Diagnosis	Third Party Third Party/Avoidant Third Party/Open	8 1 1
Communication at Time of Staging	Third Party/Avoidant Third Party Avoidant	7 2 1
Communication Throughout Treatment	Third Party/Indirect Third Party/Avoidant Third Party/Open	7 2 1
Post Treatment Communication	Direct/Open/Indirect Direct/Open/Third Party	8 2
G2 Time Period of Communication	**G2 Communication Pattern(s)**	**G2 Response Count**
Communication Before Diagnosis	Direct/Open/Indirect Direct/Open/Third Party	7 3
Communication at Time of Diagnosis	Third Party Third Party/Open	9 1
Communication at Time of Staging	Third Party/Avoidant Third Party/Open Avoidant	6 3 1
Communication Throughout Treatment	Third Party/Indirect Third Party/Avoidant Third Party/Open	8 1 1
Post Treatment Communication	Direct/Open/Indirect Direct/Open/Third Party	6 4

Note. n = 10 in each group.

Appendix C: Invitation Letter

Carol M. Baldwin Breast Care Center
3 Edmund D. Pellegrino Road Stony Brook, NY 11794

May 27, 2016

Dear Mr. Lycke:

On behalf of Dr. Hannun and the medical team, I am pleased to inform you of **approval** to conduct a qualitative research study required for your doctoral dissertation through Walden University. We look forward to assisting you in any way we can throughout your scholarly endeavor and appreciate this opportunity to consider us for your important study.

Sincerely,
Linda Bily
Linda Bily, MA, CSA
Executive Director of Patient Advocacy & Community Outreach

Cc: Yusuf A. Hannun, M.D. YAH
Together we can make a difference.
The person who says it cannot be done should get out of the way of the person doing it.

Appendix D: Recruitment Flyer

Stony Brook University Office of Research Compliance

Title of Study:

The Effects of Cancer Staging on Coping and Mother-Child Communication Patterns Among Breast Cancer Survivors

- **Purpose**: To explore and understand better the experiences and challenges of mothers who have survived early-stage breast cancer with their children.
- **Criteria for Participation**: (a) Completed treatment for early-stage breast cancer (0, IA/B, IIA/B), (b) Have pre-school aged children, school-aged children, and/or adolescents (13 - 16 years of age), (c) Have 1 ½ - 2 hours of time available for the interview.
- **Location**: This study is being conducted at the Carol M. Baldwin Breast Center at Stony Brook University Hospital, Stony Brook, NY 11795. During interviews, childcare and refreshments will be provided along with a voucher for free parking. Onsite counseling is available.
- **Anticipated Benefits**: (a) Empower mothers with additional knowledge and insight about effective communication strategies for enhancing parent-child relationships, (b) Better management of health-related stress, (c) Enhance coping skills, and (d) Build a strong "sense of self" (personal identity) through individual strengths, adversity, and motherhood.
- **Privacy and Rights**: Participation is voluntary and confidential with no identification of individuals in the final write-up of the results. With the individual's permission, audiotapes of the interview will be done to assure accuracy of information shared in the interview. Copies of the results will be shared with the participants as requested.

Appendix E: Interest to Participate in the Study Form

1. Name of Interviewee:

2. Place and Date of Birth:

3. Home Address:

4. Email:

5. Telephone/cell:

6. Marital Status:

7. Children number & ages):

8. Education:

9. Possible Group Assignment: (a) 1 ___ or (b) 2____

Date of Referral: Completed by:

Appendix F: Interview Guide

Part 1. Demographic Information

Date of Interview:

Chosen Pseudonym:

Mother's Age:

Number of Children:

Ages/Gender of Child:

Group ID: Group 1 (0/IA/IB) Group 2 (IIA/ IIB)

Part 2. The Emotional Impact of a Breast Cancer and Staging

1. Can you describe what it was like when your physician first told you of your breast cancer diagnosis?

2. What is your understanding of breast cancer staging? What emotion(s) does it evoke?

3. How did you feel at the time when the doctor confirmed your stage of breast cancer?

Part 3. The Psychosocial Implications of the Breast Cancer Experience (i.e., mothers' perceptions of the effects of a chronic, life-threatening disease on her spouse, children, family, and friends)

1. In thinking about that experience, what ways has breast cancer affected your life as a woman, wife, and mother?

2. In thinking about that experience, what ways has breast cancer affected family members and friendships?

3. Do you think knowledge of staging had an impact on how you parent - if yes, how? If not, why not?

Part 4. Coping: Descriptive Definitions (of coping, i.e., problem-focused, emotion-focused, avoidant)

1. How did you cope with stress before and after diagnosis?

2. What helped you cope during your breast cancer experience?

3. If you identified something in question 2, would you mind talking about how this may have helped you cope?

4. Do you think the breast cancer experience has made you a stronger woman, parent? If so, in what ways? If not, why not?

Part 5. Communication: Descriptive Definitions (of communication, i.e., open, direct, avoidant, indirect/third party)

1. How well did you communicate with your child(ren) before and after diagnosis and treatment?

2. How did you communicate with your child(ren) about having breast cancer?

3. Do you think having had breast cancer changed how you communicate with your child (ren)?

4. If you responded “yes” to any part of question 3, in what ways do you think changes occurred?

Concluding Questions

1. What advice would you give mothers about communicating with her child(ren) at the time of diagnosis, during treatment, and after treatment?

2. What advice would you give mothers about coping with breast cancer?

3. Is there anything you would like to add?

4. Do you have any questions?

Thank you for taking the time to participate in this study. Your contribution to this research will help professionals understand more clearly coping mechanisms among maternal breast cancer survivors and the communication needs between her and her child(ren). Therefore, taking part in this study benefits other breast cancer survivors, her child(ren), spouse, family members, and other individuals of significance.